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Lived Experiences of Women with Hidden Disabilities: A Phenomenologically Based Study

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LIVED EXPERIENCES OF WOMEN WITH HIDDEN DISABILITIES: A PHENOMENOLOGICALLY BASED STUDY

A Dissertation
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Dissertation Abstract

Lived Experiences of Women with Hidden Disabilities: A Phenomenologically Based Study

Documentation of the experiences of women with disabilities has remained sparse—benignly neglected, overlooked, and understudied in the academic fields of women's studies (gender studies) and disability studies (Depauw, 1996Article 25.1; Garland-Thomson, 2004). This qualitative study explored the lived experiences of inclusion, marginalization, and exclusion in the lives of women who have a permanent, non-visible (hidden) disability. It also explored the corporeal dimensions, such as issues of embodiment, of the lived experiences for women with hidden disabilities. Finally, this phenomenologically based study examined how women with non-visible, hidden disabilities articulated the meaning of living with an invisible disability.

The study utilized a phenomenologically based approach that incorporated in-depth interviewing, as described by Seidman (2006, p. ix). Participants were four adult women who resided in the U.S. and who were diagnosed with a long-term disability or chronic illness. The respective diagnosed conditions of each participant consisted of the following: Addison's disease, multiple sclerosis, Stargardt's Dystrophy, and unexplained infertility.

Participants articulately gave voice to their lived experiences of living with hidden chronic illnesses and/or disabilities. In terms of experiences of inclusion, a common leitmotif shared by all participants was the importance of self-advocacy in transforming a situation or experience of marginalization or exclusion into one of

inclusion. The majority of participants also addressed the role of passing, or non-disclosure, of their condition in certain contexts, particularly professional contexts.

With regards to experiences of marginalization or exclusion, the medical-health-care establishment contributed to participants' feelings of isolation, marginalization or exclusion, particularly in the time period preceding participants' receipt of their respective diagnoses. The invisibility of participants' respective conditions also contributed to feelings of marginalization or exclusion. Participants' experiences of embodiment encompassed actions and strategies, such as self-care, for pro-actively managing the physical aspects of their respective conditions.

Finally, with regards to creating meaning out of their lived experiences, participants composed a tapestry woven of shared threads. These threads carried the following themes: (a) reflections on philosophy of living; (b) turning points; (c) transformation; (d) redefining disability; and e) hopes and aspirations for the future for themselves and others.

This dissertation, written under the direction of the candidate's dissertation committee and approved by the members of the committee, has been presented to and accepted by the Faculty of the School of Education in partial fulfillment of the requirements for the degree of Doctor of Education. The content and research methodologies presented in this work represent the work of the candidate alone.

Michelle J. Yee	December 12, 2013
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Dedication

"We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time"
T.S Eliot (Four Quarters)

This work is dedicated to the memory of my late father, Don M. Yee, M.D., Ph.D., who was one of the first to teach me to listen to the voices of those who are often silenced.

Acknowledgements

In the words of Goethe, “In reality this kind of work is never finished. One has to declare it finished when, in accord with time and circumstance, one has done the utmost.” Many too innumerable to name here have made the ontogenesis and completion of this project possible and have encouraged me, even when my stamina was flagging, to do my “utmost.”

I am immensely grateful for the sage guidance, wisdom, counsel, and time of this very special academic triumvirate: my dedicated doctoral advisor and dissertation chair, Dr. Shabnam-Koirala Azad, and my supportive dissertation committee members, Dr. Xornam Apedoe and Dr. Susan Katz. They each helped to transform a potentially arduous, unfathomable journey into a unique exploration characterized by discovery and epiphany.

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Lastly, but by no means least, I want to express my profound appreciation to the remarkable women who participated in this study, as well as their families. Without the generous sharing of their invaluable time, energy, and personal stories, this work would not have been possible. Thank you.

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THE RESEARCH PROBLEM

Statement of the Problem

In the second decade of the 21st century, more than a billion people or approximately 15% of the world's population, live with a disability (World Health Organization and The World Bank, 2011). This elevated global prevalence of disability is expected to increase in the future due to two primary factors: (a) an aging population and (b) increased prevalence in chronic health conditions (World Health Organization and The World Bank, 2011). Flagrant abuses of persons with disabilities have historically remained invisible even under the lens of mainstream human rights (Melish, 2007). In their recent global report on disability, the World Health Organization (2011) proposed a number of key recommendations for further dismantling barriers that impede persons with disabilities. These recommendations included the following: (a) involving people with disabilities in the formulation and execution of laws, services, and policies; (b) strengthening and supporting research on disability; and (c) conducting research on the lives of persons with disabilities and the barriers that these individuals face (World Health Organization and The World Bank, 2011).

Women experience a higher prevalence of disability world-wide, and women with disabilities remain among the most marginalized, vulnerable members of society (WomenWatch - The United Nations Inter-Agency Network on Women and Gender Equality, 2012b; World Health Organization and The World Bank, 2011). Disabled women face obstacles and challenges arising from the dual barriers of gender and

disability (United Nations Enable, 2012; World Health Organization and The World Bank, 2011). In addition to inequitable access to employment, occupation, and economic resources, women with disabilities are at greater risk for experiencing exploitation, maltreatment, neglect, and gender-based violence (WomenWatch - The United Nations Inter-Agency Network on Women and Gender Equality, 2012b). To further compound existing risks of marginalization, women with disabilities frequently are overlooked by both disability rights advocates, as well as those advocates supporting gender equality and women's advancement (WomenWatch - The United Nations Inter-Agency Network on Women and Gender Equality, 2012a).

Women with Disabilities

The oversight of women with disabilities remains apparent in recently published research reports by research, policy, and advocacy organizations addressing gender equity and access for persons with disabilities. For example, *The Global Gender Gap Report 2012,* released as an annual publication of the World Economic Forum, did not include disability as one of its economic indicators informing economic parity and female workforce participation globally (Hausmann, Tyson, & Zahidi, 2012). The 2012 Gender Inequality Index, as promulgated by the United Nations Development Programme (UNDP), also did not include disability as an explicit variable (United Nations Development Programme, 2013). Similarly, the *2012 Disability Compendium,* published by the Rehabilitation and Research Training Center, did not include gender as a variable in its extensive compilation of statistics on disability data within the United States (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2012).

As recently as the late 20th century, documentation of the experiences of women with disabilities has remained sparse—benignly neglected, overlooked, and understudied in the academic fields of women's studies (gender studies) and disability studies (Depauw, 1996; Garland-Thomson, 2004). Disability studies examines the experience of disability as well as the lives of persons with disabilities (Pfeiffer, 2001). The specific topic area of women with disabilities seems to be a terrain of scholarship that neither gender studies nor disability studies has been eager to claim as its own. Garland-Thomson (2004) cogently highlighted this dilemma of unexplored territory:

> Even though disability studies is now flourishing…many of its practitioners do not recognize that disability studies is part of this larger undertaking that can be called identity studies…..Conversely, feminist theories all too often do not recognize disability in their litanies of identities that inflect the category of woman. (p. 73)

Garland-Thomson (2004) argued for the critical need of feminist disability scholarship in order to integrate and transform previously stratified—and segregated—academic domains:

> Academic feminism is a complex and contradictory matrix of theories, strategies, pedagogies, and practices…A feminist disability approach fosters complex understandings of the cultural history of the body. By considering the ability/ disability system, feminist disability theory goes beyond explicit disability topics such as illness, health, beauty, genetics, eugenics, aging, reproductive technologies, prosthetics, and access issues. Feminist disability theory addresses such broad feminist concerns as the unity of the category *woman*, the status of the lived body, the politics of appearance, the medicalization of the body, the privilege of normalcy, multiculturalism, sexuality, the social construction of identity, and the commitment to integration. (p. 75)

Reinforcing this particular point, Vick (2007) observed that "women's experiences are traditionally defined from the patriarchal perspective of healthy, able-bodied men" (p. 64). Ghai (2009) added that feminist discourse itself has overlooked

disabled women, even as it challenges patriarchal norms undergirding conceptualizations of women. By assuming a foundation of able-ism, feminist discourse has focused upon "issues… central to able-bodied girls and women and disability has remained an essentialist category" (Ghai, 2009, p. 286). One area in need of further exploration, which falls within the purview of feminist disability scholarship, is documentation of the lived experiences of women whose disabilities asynchronously fluctuate in visibility over time, such as multiple sclerosis ((Vick, 2007, p. 2), citing the works of Gordon, Feldman and Crose (1998) and Joachim and Acorn (2000)).

Invisible Disabilities

Invisible disabilities may be broadly defined as those impairments "which the untrained eye or casual sensibility appear to have few or otherwise vague visual markers to the outside or lay observers" (Roman, 2009, p. 678). The number of persons with invisible disabilities actually exceeds the number of those with visible disabilities, such as motor impairments (Fleischer & Zames, 2011). Examples of non-visible disabilities include speech-language-hearing disorders, neurological impairments, mental illnesses, chronic pain, auto-immune disorders, fibromyalgia, chronic fatigue syndrome, celiac disease, diabetes, asthma, and post-traumatic stress disorder (Fleischer & Zames, 2011; Jacobsson, 2011; Noonan et al., 2004; Roman, 2009; Smart, 2009). According to Judith Heumann, Special Advisor for International Disability Rights at the U.S. Department of State and an inimitable leader in the disability rights movement, invisible disabilities comprise a large portion of the disability community, yet are among the least represented (J. Heumann, personal communication, March 12, 2013).

Visible disabilities have historically overshadowed invisible disabilities within

disability studies and the international disability rights movement (Roman, 2009). Regarding this fact, Roman (2009) astutely observed:

> Disability rights-based talk and discourses too often depend on materializing visible subjects, thus privileging physical disabilities or impairments as the measure of truthful impairment in the realm of epistemic rights-based claims-making. Once visibility and veracity are equated…the knowledge of impaired bodies marked by invisible impairments drops out of sight (so to speak) of rights-based claims-making even within disability cultural politics and rights-based movements. (p. 693)

In mainstream society, the hegemony of ability and the ideal of physical perfection versus defect have resulted in "the creation of two worlds: the public world of the ordinary citizen and the hidden world of people with disabilities, who are implicitly held to have no right to inhabit the public world" (Nussbaum, 2004, p. 308). As a result of the primacy of visibility, which has become equated with veracity of disability, the very construct of disability has also become dichotomized into the stark binary terms of "abled" versus "disabled" (Lipson & Rogers, 2000; Roman, 2009).

The liminal space between the antipodes of abled versus disabled, namely a spectrum or continuum of ability, has not been formally conceptualized in disability studies. As a result, "persons with a hidden disability – discreditable people – quickly learn to navigate the liminal in-between space between "Disabled" and "Nondisabled" (Burke Valeras, 2007, p. 52). This liminal space is where the documented experiences of persons—and particularly women—with invisible disabilities may reside. The terrain of identity development for women with hidden disabilities involves a number of unique aspects. These include the phenomenon of "passing" as able-bodied, as well as external challenges regarding the legitimacy of their condition due to its lack of visibility (Gillespie, 1996; Roman, 2009; Stone, 2005; Sturge-Jacobs, 2002; Valeras, 2010).

Women with invisible disabilities are, therefore, at risk of being doubly marginalized: by mainstream society and also within the disability community itself.

Under the purview of feminist disability scholarship, a critical need remains for more studies that document the experiences of women with hidden disabilities. Within the limited corpus of literature on women with disabilities, documentation of the experiences of women with hidden (non-visible or invisible) disabilities is emergent (Stone, 2005; Sturge-Jacobs, 2002; Taylor, 2005). One area in need of further exploration, which falls within the purview of feminist disability scholarship, is documentation of the lived experiences of women whose disabilities asynchronously fluctuate in visibility over time, such as multiple sclerosis (Vick, 2007, p. 2).

Women with invisible disabilities still seem to be ensconced within zones of exclusion, which has repercussions at the sociopolitical level for participation in productive citizenship (Roman, 2009). An entrenched hegemony of visibility, whereby a disability is publicly validated only by its apparent visibility, prominently appears as a challenge to identity negotiation for women with hidden disabilities (Gillespie, 1996; Stone, 2005; Sturge-Jacobs, 2002; Taylor, 2005; Valeras, 2010). This hegemony exists in mainstream society and, ironically, even within the disability subculture itself, thereby further marginalizing women with hidden disabilities (Lipson & Rogers, 2000; Roman, 2009). Farmer (2010) observed:

> Images, stories, and first-person testimony—rhetorical strategies or documentation or both?—remain the most relied-upon means of rendering these abstract struggles personal. Personalizing human suffering can help to make rights violations real to people who are unlikely to suffer them. Sometimes the challenge is to use narrative and imagery to shift the issue from "preserving my rights" to defending the rights of the other person. (p. 490)

Background and Need for the Study

The Social Model of Disability

The social model of disability has been forwarded by disability rights activists since the 1960's and 1970's as a conceptual framework to inform policy that is more inclusive of persons with disabilities (Ghai, 2009; Lipson & Rogers, 2000; Lord, 2009; Nussbaum, 2004; Oliver, 2009; Yee, 2011). The social-human rights model of disability was developed as an alternative to the formerly predominant medical-charity model of disability (Lord, 2009; Melish, 2007). The erstwhile medical-charity model was deficit-based, focusing upon lack of ability and diagnostic categorization of impairment in order to create a parallel track of difference (Crow, 1996; Linton, 1998; Lord, 2009; Melish, 2007). With a curative orientation, the medical model of disability viewed the individual "as being in the sick role, or as being sick" with "a condition (a deficit) which is unwanted" (Pfeiffer, 2001, p. 30). As Lord (2009) observed:

> Until recently, the dominant medical and charity models viewed disability as a problem localized within the individual. These models reinforced the perception of persons with disabilities as a "broken" people whose only hope for "normalcy" lies with medical or rehabilitation experts who might "repair" them. But the medical and charity models do not reflect the perspective and experience of people with disabilities themselves. Rather, they stem from the false assumptions of the able-bodied majority, who perceive disabled people as "problems" in need of "solutions." (p. 84)

In contrast, the social-human rights model centers around concepts of ability and inclusion, with an eye toward "lifting the environmental and attitudinal barriers that prevent persons with disabilities from full inclusion and equal participation in all aspects of community life" (Melish, 2007, p. 37). This model views disability as a social construct, whereby society itself is the agent perpetuating continued disenfranchisement of persons with disabilities through entrenched negative stereotypes and non-inclusive

social policies (Fleischer & Zames, 2011; Lord, 2009). In the social model of disability, a person with a disability is no longer viewed as an individual to be "fixed" to comport with normative social standards. Rather, "a person with a disability, whether physical or psychosocial, becomes a rights-bear, like all human beings" (Lord, 2009, p. 84). At the policy level, the iconic American with Disabilities Act (ADA) and the U.S. disability rights agenda were originally premised on the social model of disability (Burke Valeras, 2007; National Council on Disability, 2008).

Notwithstanding the model's epochal strengths in aiming to empower persons with disabilities, the social model has been criticized for potentially failing to consider the entire range of lived experience with disability. Five main criticisms of the social model exist, all of which arise from the disability rights movement itself and from within disability studies (Oliver, 2009). These criticisms of the social model may be enumerated as follows: (a) inadequacy to deal with the stark realities of impairment; (b) oversight of the subjective experiences of pain associated with impairment and disability; (c) inadequacy for accommodating other social categories, such as race, class, and gender; (d) a misplaced emphasis on physical and environmental barriers as opposed to barriers arising from cultural values; and (e) inadequacy as a social theory for disablement (Oliver, 2009). For example, Taylor (2005) raised concern about the limitations of the social model of disability in light of the hidden disability experience of chronic fatigue syndrome (CFS). CFS is episodic, invisible, and is associated with negative—rather than neutral—experiences of impairment, such as pain and exhaustion. The social model of disability explicitly rejects the notion of impairment as that which inheres in an individual, defining disability instead as an interaction between an individual with his or

her environment (Crow, 1996; Taylor, 2005). Thus, the net of the social model may not be wide enough to capture the entire disability experience, particularly as experienced by disabled persons with endogenous conditions that cannot be attributable to exogenous interactions between the person and her external environment. Wendell (2001) has argued for the possibility of being more attentive to impairment while also supporting the premises of the social model of disability through a focus on "the phenomenology of impairment," a focus which differs from the deficit-based medical model's approach to disability (p. 23). This possibility also allows for the inclusion of persons with chronic illnesses under the disability rubric:

> Knowing more about how people experience, live with, and think about their own impairments could contribute to an appreciation of disability as a valuable difference from the medical norms of body and mind. Moreover, recognition of impairment is crucial to the inclusion of people with chronic illnesses in disability politics. Chronic illness frequently involves pain, fatigue, dizziness, nausea, weakness, depression, and/or other impairments that are hard to ignore. Everything one does, including politics, must be done within the limitations they present. The need to accommodate them is just as great…but they cannot be accommodated if they are not acknowledged and discussed openly. (Wendell, 2001, p. 23)

More recently, the social model of disability has been historically codified in the international arena with the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) (United Nations & Secretariat for the Convention on the Rights of Persons with Disabilities, 2013; Yee, 2011). In 2006, the UN-CRPD established an epochal agenda for change for persons with disabilities (United Nations & Secretariat for the Convention on the Rights of Persons with Disabilities, 2013; World Health Organization and The World Bank, 2011). The UN-CRPD was the first global human rights treaty that specifically addressed the rights and needs of persons with disabilities, a

group that ostensibly comprises the world's largest minority (United Nations & Secretariat for the Convention on the Rights of Persons with Disabilities, 2013; Yee, 2011). The Convention embraced the social model of disability, as noted in the Convention's Preamble: "Disability is an evolving concept and …results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (General Assembly of the United Nations, 2006, Preamble (e)). The Convention's adoption marked a watershed victory for the international disability rights movement (Lord, 2009). As of 23 October 2013, there were 158 signatories to the Convention, including the United States, and 137 ratifications (United Nations & Secretariat for the Convention on the Rights of Persons with Disabilities, 2013).

Specific sections within the CRPD are particularly pertinent to women with disabilities. Article 6 of the CRPD singularly focuses upon women with disabilities, acknowledging that women and girls with disabilities may be subject to multiple discrimination and mandating that States Parties to the convention take measures to help ensure the realization of human rights and fundamental freedoms for women with disabilities (General Assembly of the United Nations, 2006, Article 6.1). The Preamble of the Convention also recognizes that "women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation" (General Assembly of the United Nations, 2006, Preamble (q)). Finally, Article 33 of the Convention stipulates the key role of civil society, particularly persons with disabilities, in the implementation and monitoring process of the treaty (General Assembly of the United Nations, 2006, Article

33.3). However, notwithstanding all of these measures, a determinate consensus has not yet been reached regarding whether the Convention adequately encompasses and addresses the lived experiences of women with invisible (non-visible) disabilities.

Purpose of the Study

The purpose of this qualitative study was to explore the lived experiences of inclusion, marginalization, and exclusion in the lives of women who have a permanent, non-visible (hidden) disability. It also explored the corporeal dimensions, such as issues of embodiment, of the lived experiences for women with hidden disabilities. Finally, this phenomenologically-based study examined how women with non-visible, hidden disabilities articulate the meaning of living with an invisible disability.

Research Questions

This study investigated the following research questions:

1. What are the lived experiences of adult women who have a non-visible, hidden disability?
    a. What are the lived experiences of inclusion for women with hidden disabilities?
    b. What are the lived experiences of exclusion or marginalization for women with hidden disabilities?
    c. What are the corporeal dimensions (e.g., issues of embodiment) of lived experiences for women with hidden disabilities?
2. How do women with non-visible, hidden disabilities articulate the meaning of living with an invisible disability?

Theoretical Framework

Critical Disability Theory

The primary conceptual lens encompassing this study was critical disability theory. Critical disability theory addresses the broader conundrum of inclusiveness, beyond abstract rights, for persons with disabilities (Devlin & Pothier, 2006, p. 2). It does so by interrogating the following mainstream assumptions and presumptions which continue to limit full, complete participation in contemporary societal organizations by persons with disabilities: (a) the language used to frame concepts of disability; (b) contextual politics surrounding conceptualizations of disability; (c) philosophical challenges informing differing constructs of disability, such as the issue of passing as able-bodied if one has a non-visible disability; and (d) the impact that perceptions of disability make upon notions of productive citizenship, where levels of productivity become the covert criterion for citizenship (Devlin & Pothier, 2006).

According to Devlin and Pothier (2006), critical disability theory seeks to deconstruct the binary duality in mainstream perceptions of disability, namely abled versus disabled, and explores how societal norms contribute to definitions and perceptions of disability. The theory aims to illuminate how particular hegemonic norms, specifically "ableist assumptions, institutions, and structures" (p. 13) may be the predominant socially disempowering, disabling component in the lives of persons with disabilities. As Devlin and Pothier (2006) have eloquently articulated, power and context inform the central locus of critical disability theory:

> As suggested previously, issues of disability are not just questions of impairment, functional limitations, or enfeeblement; they are issues of social values, institutional priorities, and political will. They are questions of power: of who and what gets valued, and who and what gets marginalized. Critical disability

> theory interrogates a system of justice that is based on a politics of 'just us.' This is why context is so important to critical disability theory, because it is theory that emerges from the bottom up, *from the lived experiences of persons with disabilities* [emphasis added], rather than from the top down, from the disembodying ivory tower. As such, it is a form of embodied theory. But this does not mean critical disability theory does not engage with some of the big questions of philosophy and political theory; it simply means that it comes at them with a sharp awareness of the contexts of inequality based on disability. (p. 9)

Material Feminism

An examination of the role of gendered norms in society's construction of disability is emergent with critical disability theory. To remedy this theoretical gap, the lens of feminist theory was overlaid on the lens of critical disability theory. This overlay had the potential to illumine normative constructs of gender that may be negatively limiting or reducing complex issues of identity and ontology for women with hidden disabilities (Alaimo, 2008; Hekman, 2010). In addition, this overlay also worked to address the extant gap in feminist articulations on the body. By directly confronting the previously overlooked "experience of the negative body" (Wendell, 1996, p. 166) a "feminist understanding of bodily suffering" (Wendell, 1996, p. 166) could be further developed. Such an understanding falls under the broader rubric of "the phenomenology of bodily suffering" (Wendell, 1996, p. 170). As Garland-Thomson (2004) has observed, "a feminist disability approach fosters complex understandings of the cultural history of the body" (p. 75). Such an approach encompasses feminist concerns such as the status of embodiment and the lived body, the medicalization of the body, the social construction of identity, cultural primacy of normalcy, and the politicization of appearance.

Specifically, a lens of material feminism was utilized (Alaimo & Hekman, 2008b; Hekman, 2010). Material feminism grants an exploration and examination of the role of

material, non-discursive factors, both endogenous and exogenous, informing women's lived experiences in material bodies, including those marked by pain and chronic illness (Alaimo, 2008; Alaimo & Hekman, 2008a; Hekman, 2008). This recent pivot to a material focus in feminist theory has allowed for the following possibilities which had been previously foreclosed: (a) rethinking the materiality or constitution of bodies and natures; (b) seeking definitions of human corporeality which include the interaction of discursive and material elements in bodily constitutions; and (c) launching from a position of material substances while also considering the role of social construction (Alaimo & Hekman, 2008a).

This recent turn toward materiality is a reaction to linguistic or social constructionism without conceding to essentialism (Hekman, 2010). Material feminists attempt to accomplish "what the postmoderns failed to do: a deconstruction of the material/discursive dichotomy that retains both elements without privileging either" (Alaimo & Hekman, 2008a, p. 6). In this sense, materiality thus encompasses the interaction between bodies, each of which has differentiated shapes and capabilities, and the various components of the external environment (Garland-Thomson, 2011, p. 594). Beyond the materiality of a human body are material-discursive factors that contribute to overall processes of materialization; these include factors typically categorized as social, economic, natural, physical, geopolitical, and biological (Barad, 2008, p. 128). In the words of Alaimo (2008):

> Without diminishing the specificity of living as a chronically ill person, there is obviously a sense in which all embodied beings experience corporeal agencies, be they positive, negative, or neutral. Acknowledging that one's body has its own forces, which are interlinked and continually intra-acting with wider material as well as social, economic, psychological, and cultural forces, can not only be useful but may also be ethical. In the most obvious sense, if one cannot presume

> to master one's own body, which has "its" own forces, many of which can never be fully comprehended, even with the help of medical knowledge and technologies, one cannot presume to master the rest of the world, which is forever intra-acting in inconceivably complex ways. (p. 250)

Phenomenology

The final, tertiary conceptual lens informing this qualitative study was phenomenology, particularly as articulated by Van Manen (1990) and Seidman (2006). Phenomenology is concerned with understanding the nature of lived experience (van Manen, 1990, p. 42). It does not attempt to construct a theory by which to explain the natural world. According to van Manen (1990), phenomenological research comprises the following research foci: (a) addressing the nature of lived experience; (b) investigating lived experience rather than conceptualizations of experience; (c) and reflection upon key themes that characterize the phenomenon (p. 30). Phenomenology attempts to unearth the range of possible insights regarding the world as it is immediately experienced, without a priori or posteriori conceptualizations, taxonomies, categorizations or reflections (van Manen, 1990).

Through a phenomenological lens, lived experience has two facets: ontic (concreteness) and ontological (the essential nature) (van Manen, 1990, pp. 39-40). The focus or topic of phenomenological inquiry is itself informed by "the questioning of the essential nature of a lived experience: a certain way of being in the world" where "the term 'essence' may be understood as a linguistic construction, a description of a phenomenon" (p. 39). In-depth interviewing with a phenomenological lens and orientation may further enhance the understanding of the lived experience of others, as

well as the very meaning ascribed to that experience by those who live it (Seidman, 2006, p. 6).

Significance

This study privileged the voices of women whose voices may have been silenced, marginalized or excluded. Freire (1970) has observed:

> Because dialogue is an encounter among women and men who name the world, it must not be a situation where some name on behalf of others. It is an act of creation; it must not serve as a crafty instrument for the domination of one person by another. The domination implicit in dialogue is that of the world by the dialoguers; it is conquest of the world for the liberation of humankind. (p. 89)

In addition to privileging these voices and providing a forum for creative dialogue, this study, through its results, contributes to the extant paucity of literature on the lived experiences of women with non-visible disabilities.

The study also has the potential to contribute valuable insights to extend the contour of domestic disability policy to more specifically address the needs of women with hidden disabilities. The American with Disabilities Act (ADA) was originally premised upon the social model of disability (Burke Valeras, 2007; National Council on Disability, 2008). However, this particular model has been interrogated for possible oversight of all aspects of the disability experience, such as the hidden disability experience of chronic fatigue syndrome (Taylor, 2005).

Results from this study may also extend the dialogue and development of international human rights standards and norms, such as those codified in the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD), to further protect the rights of women with hidden disabilities (General Assembly of the United Nations, 2006). A focus on individual need, which comports with the human rights'

framework's attention to the protection of individual dignity, may effectively inform the broader realm of group-based need (Stein, 2007, p. 119). Specific sections within the UN-CRPD are particularly pertinent to women with disabilities. An issue that has not been intensively explored is whether the Convention adequately encompasses and addresses the lived experiences of women with invisible (non-visible) disabilities. Results of this study may potentially contribute to starting a needed dialogue around this critical issue.

Definition of Terms

Disability refers to a "social location complexly embodied" (Siebers, 2011, p. 14). The term also encompasses a minority and cultural identity (p. 4) that "is not a pathological condition, only analyzable via individual psychology" (p. 11). According to Pfeiffer (2001), disability may be defined by its antipode, namely what disability is not. From this perspective, disability cannot be equated with the following: (a) a tragedy; (b) loss of productivity, value, social worth; (c) an unnatural part of life; and (d) homogeneity (p. 44).

Visible disability may be defined as any disability that is readily apparent or observable to the observer (Wendell, 1996, pp. 13, 70).

Invisible (hidden) disability may be defined as those impairments "which the untrained eye or casual sensibility appear to have few or otherwise vague visual markers to the outside or lay observers" (Roman, 2009, p. 678). Examples of invisible or hidden disabilities may include the following: (a) autoimmune disorders; (b) multiple sclerosis; (c) myasthenia gravis; (d) diabetes; (e) rheumatoid arthritis; (f)

lupus; (g) asthma; (h) speech-language-hearing issues; (i) traumatic brain injury (TBI); (j) post-traumatic-stress-disorder (PTSD); (j) attention deficit disorder (ADD); (k) stroke (cerebrovascular disorder); (l) cancer; (m) mental illness; (n) chronic fatigue syndrome (CFS); (o) HIV/AIDS; and (p) Celiac Disease.

Embodiment may be broadly defined as one's relationship to—and experience with—one's own differentiated body across the vicissitudes of changing conditions in health, maturation, and impending mortality (Do & Geist, 2000; Westhaver, 2000).

Phenomenology may be broadly defined as the study of lived experience with an aim toward "gaining a deeper understanding of the nature or meaning of our everyday experiences" (van Manen, 1990, p. 9).

Material feminism refers to a recent, novel pivot in feminist theory to focus upon the realm of the material (Alaimo & Hekman, 2008a, p. 7). As such, theories with a material feminist lens explore conceptions of "human corporeality that account for how the discursive and the material interact in the constitution of bodies" as well as the "interaction of culture, history, discourse, technology, biology, and the 'environment,' without privileging any one of these elements" (Alaimo & Hekman, 2008a, p. 7).

CHAPTER II

THE REVIEW OF THE LITERATURE

Overview

This literature review first provides an overview of the disability paradigm, including a critique of the social model of disability and alternatives to the social model. The review then addresses embodiment, a key identity process for women with visible disabilities. That discussion then is augmented by a brief portrait of the differential landscape of the unique processes in identity transformation for women with invisible disabilities. These include passing and issues of legitimacy of the disability in light of the disability's non-visible nature.

The Disability Paradigm

Pfeiffer (2001) provided a concise synopsis of the nine various versions of the disability paradigm, which is the modern counterpoint to the erstwhile medical model of disability. The medical model of disability has historically "studied disability in terms of deficits in a person which kept that person from carrying certain functions and activities" (Pfeiffer, 2001, p. 30). In contrast, the disability paradigm evolved out of the disability rights movement and propounds that disability is the result of an interaction between an individual and his/her environment.

Nine interpretations of the disability paradigm are briefly summarized in Table 1 below. The social model of disability is one interpretation of the disability paradigm.

Table 1

Nine Interpretations of the Disability Paradigm (Pfeiffer, 2001)

Version of the Disability Paradigm	Key Premise(s)
Social Construction (United States)	Disability is a social construct; Environmental factors can play a role in the social construction of disability identity
Social Model (United Kingdom)	Informed by a class perspective, this model holds that society bears the onus to provide adequate services for the disabled and to include the needs of persons with disabilities in social structures
Impairment	Still inchoate, this version argues for the inclusion of impairment and personal experience into the social model
Oppressed Minority (Political)	Persons with disabilities face ongoing discrimination in their daily lives; they are thus denied many rights and access to social, cultural, and economic capital
Independent Living	As a philosophy and a movement, this version regards persons with disabilities are responsible agents for themselves; endowed with agency and self-determination, they must be granted the right to choose
Post-Modernist, Post-Structuralist, Existential	Genesis of this version lies in cultural studies; the lens of culture, as both a social and political construct, may be applied to examine the experience of disability
Continuum	As an emergent, proto-version, it holds that different representations of disability exist and that these are both inter and intra-related to each other

Human Variation	Disability is multidimensional in nature and impairment is heterogeneously complex; the capacity of social systems currently are limited in adequately addressing the entire range of human variation
Disability as Discrimination	Discrimination is the unifier of all the above versions; disability is a policy concern, rather than a health or medical concern

In Pfeiffer's view, disability "is a natural part of life, everyone's life" (Pfeiffer, 2001, p. 44). This view is consistent with an emergent redefinition of disability as one feature of a typical life span where disability exists on a spectrum, rather than as a discrete, antipodean point to normality (Fleischer & Zames, 2011, p. 255). Disability therefore cannot be equated with dependency, tragedy, loss of productivity or social contribution. The conundrum of disability is that the very label of disability itself typically originates from an external diagnosis rather than self-identification. To add to this conundrum, answers remain inchoate in response to the universal question on how to identify and measure disability. Pfeiffer concluded that future research based on the disability paradigm, in all of its diverse manifestations, needs to be inclusive of disabled persons as active partners and agents in the research process.

Disability theory has historically embraced the assumption that there is an essential identity unique to the disabled, while also acknowledging that this disabled identity itself will be stigmatized, minimized, and marginalized within the context of society at large, a relegated status resisted and challenged by disability rights activists (Ghai, 2009; Nussbaum, 2004). Among the documented challenges faced by persons with disabilities are those of stigma, social oppression, political disenfranchisement, and

marginalization, including economic marginalization (Ghai, 2009; Lipson & Rogers, 2000; Nussbaum, 2004). Even the very term "disability" is socio-politically marginalizing, given that the prefix "dis" is connoted semantically with "dys"-function, deficit, negation or variation from a sociocultural norm.

Regarding definitions of disability, the varied connotations associated with the term *disability* reflect layered, changing perceptions toward variations from culturally-sanctioned concepts of "normalcy," where "normal" is a heteronomous, socio-culturally defined standard (Linton, 1998). According to Vick (2007), "conceptually, there is no single scientific definition, framework, or language with which we can situate the experience of disability"(p. 2). However, by re-framing disability as a socio-political construct, disability rights activists and disability studies scholars have worked to liberate the term *disability* from the definition characterized by medicalization, with an over-emphasis on deficits, atypical symptoms, and impairments (Linton, 1998). This conceptual divestiture has been reflected in the recent movement away from the medical model of disability and toward the social-human rights model of disability.

Consistent with critical disability theory, the social model of disability has been forwarded by disability rights activists as a conceptual framework to inform policy formulation that is more inclusive of persons with disabilities (Ghai, 2009; Lipson & Rogers, 2000; Lord, 2009; Nussbaum, 2004; Oliver, 2009; Yee, 2011). The social model and disability-human rights model have recently been combined into one collective term, the "social-human rights" model (Melish, 2007, p. 43). However, the term can be semantically de-coupled (Asch, 2004; Pfeiffer, 2001; Shakespeare & Watson, 2001; Stein, 2007). This de-coupling is further detailed below in the next two sections.

Critiques of the Social Model of Disability

Introduction

As noted in the previous chapter, the iconic American with Disabilities Act (ADA) and the U.S. disability rights agenda were originally premised on the social model of disability (Burke Valeras, 2007; National Council on Disability, 2008). The ADA, which marked its 23rd anniversary in the U.S. on July 26, 2013, may be regarded as one of the most comprehensive pieces of disability rights legislation (Edwards, 2013). In addition to the ADA, the social model of disability was recently codified at the international level in 2006 with the landmark adoption of the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) (United Nations & Secretariat for the Convention on the Rights of Persons with Disabilities, 2013; Yee, 2011). The Convention's adoption, with its core integration of the social model of disability, signified a turning point in the public sphere away from the former disenfranchising medical model of disability (Lord, 2009) Specifically, the treaty articulated a perspective of disability where persons with disabilities are empowered to be rights-bearers (Lord, 2009). Hence, the social model of disability has now become the dominant model informing the dialogue around disability rights at both the national and international levels.

Primary Lacuna in the Social Model of Disability

Crow (1996) made this astute observation two decades before the social model was codified in the UN-CRPD:

> It [the social model] has played a central role in promoting disabled people's individual self-worth, collective identity and political organization. I don't think it is an exaggeration to say that the social model has saved lives. Gradually, very gradually, its sphere is extending beyond our movement to influence policy and practice in the mainstream. The contribution of the social model of disability, now and in the future, to achieving equal rights for disabled people is incalculable. So how is that, suddenly, to me, for all its strengths and relevance, the social model doesn't seem so water-tight anymore? It is with trepidation that I criticize it. However, when personal experience no longer matches current explanations, then it is time to question afresh. (Crow, 1996, p. 56)

To expand upon Crow's perspective, a primary criticism of the social model of disability has been its oversight of impairment (Asch, 2004; Crow, 1996; Hickey-Moody, 2008; Pfeiffer, 2001; Shakespeare & Watson, 2001). In light of this lacuna, Hughes (2008) argued for a phenomenological approach to disability as an alternative to a post-humanist approach**.** This oversight of impairment is concomitant with non-acknowledgment of corporeality, including embodiment, in the lived experience of disability (Hickey-Moody, 2008). More specifically, hearkening back to earlier feminist discussions on 'nature' versus 'culture,' Hickey-Moody (2008) highlighted the problematic dialectic between social construction and embodiment in the social model with this observation: "Embodied experiences and the ways we think about, and refer to, bodies need to be understood as constituting valid and powerful sites of knowledge production" (p. 359).

In addition, this oversight can be found in both the social constructionist version of the disability paradigm, which originated in the United States, as well as in the United Kingdom's version of the social model, which is class-based (Pfeiffer, 2001). Shakespeare and Watson (2001) explored the academic and political debates over the social model of disability within Britain and the United Kingdom. They covered three

main criticisms of the British social model of disability: (a) the key issue of impairment; (b) the unsustainable dichotomization between impairment and disability; and (c) the fundamental issue of identity, including the complexity of multiple identities with regards to gender, race, and sexuality in relation to disability. Regarding the first two points, Shakespeare and Watson trenchantly observed that "impairment is only ever viewed through the lens of disabling social relations" (p. 18). Moreover, it may be physically impossible to exactly demarcate where disability starts and where impairment ends. More explicitly, Shakespeare and Watson opined:

> While impairment is often the cause or trigger of disability, disability may itself create or exacerbate impairment. Other impairments, because invisible, may not generate any disability whatsoever, but may have functional impacts, and implications for personal identity and psychological well-being. (p. 18)

Given this observation, Shakespeare and Watson argued for dismantling the dichotomized view of impairment and disability with a view towards integration. From their perspective, illuminating the requisite connection between impairment and embodiment can facilitate this process of integration. Disability and impairment may then be viewed as different locus points on a continuum or, alternatively, as different facets of one experience (Shakespeare & Watson, 2001, p. 22).

Alternatives to the Social Model of Disability

In light of the impairment lacuna in the social model of disability, the human variation model has been forwarded as one alternative to the social model. Asch (2004) has argued in support of a human variation model for persons with a range of impairments. Drawing upon critical theory, Asch provided a unique perspective that supports the social model of disability while simultaneously acknowledging the

heterogeneity of impairments and the visibility or observed perception of impairments. Asch theorized that an impairment or disability is socially constructed; yet, impairments could impact individuals differentially.

> Instead of discussing impaired individuals, attention should go to determining which environments—which social, physical, bureaucratic, and communication structures—could incorporate the widest array of individuals in all their diversity of capacities and then determine which environments were impairing and how they could be modified. (Asch, 2004, p. 17)

Using a human variation lens, overlaid upon the social model of disability, Asch thus illuminated the key issue of how extant environments and social arrangements may contribute to society's failure to facilitate and foster inclusive participation by all members of society (p. 22).

Stein (2007) concisely summarized the social model of disability and its role in international disability rights law:

> The social model of disability asserts that contingent social conditions rather than inherent biological limitations constrain individuals' abilities and create a disability category. Beginning in the 1970s, international soft laws addressing disability have increasingly adopted precepts from the social model. Nevertheless, because advocates have limited the social model to formal equality theory, its application is limited within the human rights arena. (p. 85)

Stein (2007) simultaneously addressed the limitations of the social model of disability and then extended this model into a novel, more comprehensive disability human rights model. Stein identified two key limits of the social model: (a) its reliance upon the notion of corrective justice and (b) the model's focus upon first-generation rights, namely civil and political rights, rather than including second-generation rights, such as economic, social, and cultural rights. Regarding the first point, the social model has had the unexpected challenge of overcoming mistaken, but strongly held,

assumptions that society justifiably excludes persons with disabilities due to their innate limitations. This challenge arises from the model's principal premise that a socially constructed environment, along with underlying attitudes supporting this construction, are the primary factors responsible for creating disabling conditions. Regarding the second point, the model has been inclusive of civil-political rights, which may equalize treatment. Yet the model has neglected to adequately address second-generation rights, such as economic, social, and cultural rights. These second generation rights equalize opportunity based on an assumption of "equal humanity" rather than "levels of functional sameness" (p. 92). In equalizing opportunity, the realization of second-generation rights also "allows for individual differences among people with disabilities" (Stein, 2007, p. 92).

In light of these two gaps in the social model of disability, Stein (2007) cogently argued for a disability human rights framework as a bridge from group-based protection to individualized assessment and needs. The disability rights paradigm, in all of its diverse versions, operates under the assumption that rights progress from the group to the individual. In contrast, a *disability human rights* (emphasis added) paradigm integrates the strengths of the social model of disability, namely the emphasis upon society's role in creating the construct of disability and in rectifying any social sequelae from this construct, along with these two additional models: the human right to development and Martha Nussbaum's capabilities approach. The human right to development combines both first-generation (negative) rights, namely civil and political rights, with second-generation (positive) rights, namely social, cultural, and economic rights. Nussbaum's capabilities approach emphasizes the provision of means for individual self-development

(Nussbaum, 2000). In Stein's perspective, by "combining the best elements of the social model of disability, the human right to development, and Nussbaum's capabilities approach, the disability human rights paradigm provides a comprehensive framework for ensuring the development of individual talent" (Stein, 2007, p. 106).

Experiences of Women with Physical Disabilities

Embodiment

Within explorations of identity in disability studies, the issue of embodiment surfaces as a central theme, particularly for individuals who are living with a physical disability (Do & Geist, 2000; Westhaver, 2000; Zitzelsberger, 2005). What is embodiment? Embodiment may be broadly defined as one's relationship to—and experience with—one's own differentiated body across the vicissitudes of changing conditions in health, maturation, and impending mortality (Do & Geist, 2000; Westhaver, 2000). Disembodiment, as the counter-point to embodiment, may result from an alienation to one's body and self, an alienation informed by able-ism and negative, stereotyped public perceptions of a differentiated or disabled body.

> The intimacy and otherness of our bodies is represented in the duality of embodiment and disembodiment and the duality of presence and absence we experience in wellness and illness, in ability and disability. Essentially, everyone experiences the duality of embodiment and disembodiment.
> Embodiment and dis-embodiment are natural processes that operate everyday, habitually, often unconsciously.
>
> (Do & Geist, 2000, pp. 52-53)

For individuals with physical disabilities, the body as a pivotal site of resistance and struggle emerges as a critical theme within examinations of embodiment (Do & Geist, 2000; Westhaver, 2000). Do and Geist (2000) strongly support the role of communication as a transformative vehicle to cross boundaries between embodied and

dis-embodied selves and to minimize alienating dis-embodiment. Communication, especially the personal narratives of persons with disabilities, can function as a means to resist and replace dominant, public narratives of disability that are de-legitimizing and marginalizing. As an example, the researcher, who was herself diagnosed with polio in early childhood, details when she became aware of the self-imposed limitations she had placed upon herself (Do & Geist, 2000). This sojourn of moving from a disembodied identity, initially associated with her disability, into an empowered, embodied identity fortunately occured at a young age for Do. Only after being pushed beyond her comfort zone by her kindergarten teacher (e.g., to complete a simple physical task, namely retrieving a carton of milk for herself without depending on help from her peers) did Do begin to shed self-imposed, circumscribed limitations, limitations which reflect society's perceptions of her physically differentiated body.

Sites of Resistance and Acquiescence

In a phenomenological study of adult women with congenital, physical disabilities (e.g., paraplegia, differentiated gait, visual impairments, and albinism), constrasting "sites of resistance and sites of acquiescence" with respect to the "societal code of disability" (Westhaver, 2000, p. 92) surfaced in participants' discussions of embodiment and difference (Westhaver, 2000). According to Westhaver's analysis, the sites of resistance relate to female participants' openness to perceive and define their differentiated bodies at an autonomous, individual level independent of heteronomous, social norms. In contrast, sites of acquiescence were evident where negative perceptions of a differentiated body became assimilated or integrated into participants' self-perceptions of their bodies, comprising themes of rejection, skepticism, and overt

difference (Westhaver, 2000). Connecting to these two contrasting poles are four sub-themes, including 'not different" (i.e., 'normal'), 'different', 'rejection', and 'acceptance.' These sub-themes illuminate the conflicted, complex, and contradictory aspects of identity transformation for women with physical disabilities.

> As women with disabilities speak their bodies, new sites of spoken discourse give rise to an understanding of the lived experience of inhabiting a differentiated body as conflicting and multidimensional. Within the everyday lives of women with disabilities are constant reminders of their position as outsiders in the discursive arenas within which ableism and femininity are ideals.
>
> (Westhaver, 2000, pp. 97-98)

These conflictual aspects seem to arise from mixed reactions in self-identification as an individual with a disability, coupled with the range of reactions to their disability from others. Westhaver (2000), in her phenomenological analysis, observes that this tension in identity negotiation reflects multiple pairs of binary oppositions in meaning. Westhaver identifies four binary oppositions: ability-disability; mind-body; masculinity-femininity; and the public-private world. These oppositions ostensibly represent hidden cultural codes that undergird the hegemony of able-ism and social norms of femininity; this hegemony becomes consciously or sub-consciously articulated in participants' discourse about their bodies.

Zitzelsberger (2005) provided additional articulation concerning this tension between the public-private worlds that Westhaver (2000) identifies. Using a modified constructivist grounded theory approach, Zitzelsberger (2005) explores ways in which women with physical disabilities and differences experience their bodies in daily life. Findings are presented via descriptions of three processes: 1) imposing in/visibility; 2) negotiating in/visibility; and 3) seeing differently/transforming. In light of these three themes, Zitzelsberger highlights the following issues:

- the incongruity between self-perception and others' perceptions of the embodiment of their disability/ difference
- negative associations connoted with different embodiments, such as heightened visibility (hyper visibility) in the public social sphere of one's differentiated body commensurate with increased invisibility of the self in this same public sphere
- active rejection of others' perceptions of their differences when these perceptions are viewed through the hegemonic, colonizing cultural discourse and lens of able-ism or the dominant culture

Similar to Westhaver's (2000) phenomenological interpretation, Zitzelsberger (2005) discussed this recursive connection of invisibility and hyper visibility for women with visible disabilities—and their experiences of embodiment with their differences—as a consequence of normative, hegemonic representations of acceptable bodies and the interaction of these representations with individuals. "In acknowledging both disability and gender as discursive constructs with lived effects, the women were engaged in interlocking effects of multiple and conflicting discourses of gender, disability and difference" (Zitzelsberger, 2005, p. 400).

Challenges for Women with Hidden (Non-Visible) Disabilities

Invisible disabilities may be broadly defined as "those to which the untrained eye or casual sensibility appear to have few or otherwise vague visual markers to the outside or lay observers" (Roman, 2009, p. 678). In addition to issues of embodiment, there are unique aspects to navigating the terrain of identity development for women with disabilities that are not visibly apparent. These include passing and external challenges regarding the legitimacy of their condition due to its lack of visibility. Both of these

issues connect to the hegemony of visibility in mainstream culture. Samuels (2003) describes this hegemony as "the dominant culture's insistence on visible signs to legitimate impairment" (Samuels, 2003, p. 245).

In her essay addressing invisible disability and the limits of discourse related to coming-out, Samuels (2003) addressed three issues related to issues of disability and visibility. These issues were the following: (a) the "analogizing of social identities" (p. 233), with particular reference to feminist, queer, and disability studies; (b) the politics of visibility and invisibility, including the phenomenon of passing in different social contexts; and (c) a brief exploration of the invisible identity of a nonvisible disability.

Regarding the first issue, Samuels (2003) observed that creation and reliance on false dichotomies has informed many of the analogies regarding disability. These false dichotomies "not only produce inequality between the terms of comparison but exclude or elide the anomalous experiences that do not fit easily within their terms" (p. 235). Regarding the second issue of the politics of invisibility and visibility, Samuels addressed the social condemnation of passing. Such condemnation seems to be particularly pointed toward persons who are invisibly disabled. These condemnations frequently merge two separate dynamics: (a) deliberately passing as non-disabled; and (b) passing by default. In the words of Samuels, "the perception persists that non-visibly disabled people prefer to pass and that passing is a sign and product of assimilationist longings" (p. 240). The last section of Samuels' essay touched upon issues of legitimacy. Persons with nonvisible disabilities face a number of unique challenges that arise from the hegemony of visibility. These include tenuous inclusion within the disability community itself and ongoing work to secure adequate benefits and accommodations. Notwithstanding the heterogeneity of nonvisible disabilities, Samuels observed that "a reading

of numerous narratives across impairments suggests a common experience structured by the disbelieving gaze of the normate" (Samuels, 2003, p. 245).

Passing

Gillespie (1996) defined *passing* as any behavior that disguises or minimizes a person's physical disability during social interactions; reliance on passing is the degree to which disabled persons manage impressions of their disabilities by passing. Gillespie investigates indicators of passing among persons with disabilities (PWD) in an attempt to better define and operationalize passing. More than half of the participants in Gillespie's study were female; disabilities comprised a variety of visible and invisible disabilities, as well as both congenital and acquired conditions. Gillespie suggests that a continuum of passing exists in light of both quantitative and qualitative results. Quantitatively, no indicators were found to be statistically significant. However, results of her study confirmed two previously identified forms of passing, namely aggression/defensiveness and compensation/overachieving. Gillespie also identified three additional forms of passing: selective avoidance of certain categories of people, selective avoidance of certain categories of situations, and self-deprivation. Suprisingly, those participants with an invisible disability expressed desire for a more visible disability in order to facilitate public perception and understanding of their disability. This last unexpected result seems to support a recent observation made by Siebers (2011):

> Passing exists in two perspectives, the point of view of the disabled and the nondisabled. The first tells a story to the second, but each side expresses a desire, the desire to see disability as other than it is. The question is whether it is the same desire on both sides, whether there are resources for interfering with the desire to pass, whether other stories exist. (p. 119)

Legitimacy

Vickers (2001) phenomenologically documented the experiences of eight mid-career women with non-visible, chronic illness. Illnesses comprised a range that included breast cancer, multiple sclerosis, chronic fatigue syndrome, endometriosis, and glaucoma. The combined lenses of gender and workplace were used to contextualize the stories of chronically ill women who balanced full-time work and responsibilities at home, including care-giving. Vickers wrote that "these are women who are, frequently, in-between traditional notions of wellness and sickness, in-between the extremes of junior and senior in organisational life, and in-between home and work, as they struggle with the confines and predicaments that chronic illness inevitably brings" (n.p.). The researcher herself was a mid-career professional woman with an invisible, chronic illness, namely multiple sclerosis.

Issues raised by the participants in Vickers' (2001) study encompassed the complex balancing act of multiple responsibilities, including both career (public) and domestic (private) responsibilities. Adding to the complexity were the dually layered variables of gender (female) and the management of a chronic illness, replete with fatigue and pain, all of which were not overtly visible to colleagues. Lack of knowledge by others regarding the non-visible illness contributed to the lack of social validation experienced by the participants. Vickers persuasively concluded her study with these words:

> The benefit of sharing these stories is through, at least, some recognition and acceptance of what they have endured. Stories such as these are important for their own sake. Events that are difficult, painful and taxing are real for the individuals recounting them – whether or not those who cannot be in their shoes recognize this or not. (Vickers, 2001)

Roman (2009) examined and critiqued three public pedagogical media campaigns that were aimed at raising awareness about the needs of women with invisible disabilities. These three campaigns included: (a) the U.S. televised campaign of The Centres for Disease Control and Prevention to educate the public about chronic fatigue syndrome; (b) the 2008 Canadian Mental Health Association's television campaign to highlight awareness of mental illness; and (c) the performance work of the actor Victoria Maxwell, whose plays and monologues address the issues of living with bipolar disorder (Roman, 2009). Roman holds that "such campaigns are texts that coordinate and organize the meanings of citizenship and the zones of inclusion/exclusion" with educational, economic, and political implications (p. 679).

With the exception of the third campaign, these public media campaigns included subtle images and assumptions that favored the hegemony of the visible, equating visibility with veracity and invisibility with non-productive passivity (Roman, 2009). These cultural assumptions, which also have permeated the disability rights movement, further marginalize and de-legitimize women with invisible disabilities/ impairments by fostering an attitude of ambivalence toward persons with invisible disabilities:

> Women with invisible disabilities face some unearthed challenges and paradoxes: bodies with physical impairments are conventionally read as truthful markers of impairment, which allow non-disabled viewers/consumers a way to perform a kind of easy no-contact-required authenticity check for the truthfulness of disability experiences. (Roman, 2009, pp. 677-678)

Valeras (2010) offers one of the few contemporary studies addressing identity negotiation for persons with invisible disabilities. This published work draws upon Valeras' (2007) unpublished doctoral dissertation on understanding identity processes and self-disclosure decisions of persons with hidden disabilities. Research participants

were three women and three men, aged 21 to 53 years, who had experienced symptoms of a non-visible, physical medical condition before adolescence. Hidden disabilities of the participants included muscular dystrophy, diabetes, asthma, juvenile rheumatoid arthritis, celiac disease, and epilepsy (seizure disorder). Utilizing narrative research methodology, Valeras conducted in-person, two-hour recorded conversations with participants. Participants further collaborated with the researcher in answering these additional questions following preliminary data analysis: "How does an unapparent medical condition affect identity?" and "How are self-disclosure decisions negotiated?" Results were analyzed via narrative analysis and presented according to identified themes: disability identity, the spectrum between abled and disabled, passing and bi/ability, a desire not to be "different", and tension between passing, disclosure of public and private selves, and impression management. In her discussion of results, Valeras (2010) observed that persons with invisible disabilities positively identify with the concept of a spectrum of ability between abled and disabled. Unfortunately, this conceptualization of an ability spectrum does not formally exist and does not have the support of either the disability community or the able-bodied; dichotomization of ability has been predominant in identity politics of disability.

Visibility serves as an iconic marker of disability. In particular, "visibility of disability is central to characterizing disability as unusual," observes Valeras (2010, p. 10, citing Goffman, 1963). The non-visibility of disability for persons with hidden disabilities thus poses a challenge to the very legitimacy of their impairment(s) or health conditions. Both Sturge-Jacobs (2002) and Stone (2005) addressed this conundrum of visibility for women with invisible disabilities. Sturge-Jacobs (2002) conducted a

phenomenological study of nine women who had a diagnosis of fibromyalgia (FM) for longer than 12 months. She reported that her study confirmed previous studies' findings regarding the lack of validation and legitimacy that persons with invisible disabilities experienced secondary to the less visible presentation of their impairment(s). Key issues emerged. These were the incongruity between appearance and actual physical pain secondary to FM, the vicissitudes of unpredictability when living with a chronic illness, attempts to normalize including attempts to conceal their disability, and mourning losses. As a principal source of stress for the women, "the dilemma of how well they looked in relation to how unwell they felt was a cause of conflict not only for themselves, but also for other family members, friends, physicians, and employees…After all, they looked the same" (Sturge-Jacobs, 2002, p. 29).

Similarly, Stone (2005) explored, in a qualitative study, how young female stroke survivors experience the reactions of others—post-rehabilitation—and the impact of such reactions on quality of life and navigation of their social environment. Participants in this study were 22 adult women who had survived hemorrhagic stroke for a duration range of 3 to 34 years; some of the participants had experienced the stroke in childhood. Most participants were not visibly disabled, but all could be considered to have an invisible disability secondary to sequelae resulting from the hemorrhagic stroke. With regards to the latter point, Stone (2005) wrote, "These visibly disabled participants are included here because they also have invisible disabilities. Their inclusion works to underscore the point that many people have a variety of disabling impairments, and the impact of these impairments may not necessarily be related to whether they are immediately visible" (p. 296). Of significance is the fact that the researcher herself survived a hemorrhagic stroke

in her childhood at age 11.

Notable contributions of Stone's (2005) study, pertinent to the emergent literature on women with hidden disabilities, included the following: a) the researcher's acknowledgment of the co-existence of visible and invisible disabilities with participants; b) an overview of the problem of invisible disabilities—namely the "hegemony of dualistic thinking" (Stone, 2005, p. 294) between abled versus disabled; c) the dilemma of living in the liminal space "in between" abled versus disabled, even though not chronically ill, a dilemma to which Valeras (2010) and Vick (2007) have previously alluded ; and d) discussion of the hegemony of visible disabilities in contributing to the formation of a disability identity and its validation. Regarding this last point about the hegemony of visible disabilities, Stone (2005) observed in her analysis that "each woman compares her own invisible disabilities to the visible disabilities of others. It seems, then, that even these women accept the hegemonic understanding that disability must be visible, or at least, the only disability worth taking seriously is visible" (p. 303).

Similar themes in identity navigation also surfaced in a participatory research project exploring the experience of persons with the invisible disability of chronic fatigue syndrome (CFS) (Taylor, 2005). All participants met established criteria for CFS, and the majority (96%) of participants were female. Taylor identified four major themes that encompassed challenges faced by the participants in their experience of living with CFS across the contexts of work, home, and community. The first theme was particularly consistent with challenges of an invisible condition that were also identified by Valeras (2010), Sturge-Jacobs (2002), and Stone (2005). These four themes were: a) minimization and diminishment of their disability by others, including health

professionals, secondary to the fluctuating nature of CFS and the invisibility of CFS as a condition; b) negative experiences with impairment, including debilitating exhaustion, pain, and cognitive challenges; c) lack of identification with the disability community and circumspect, tentative adoption of a disability identity due to the episodic nature of CFS; and d) advocacy for increased recognition and validation of CFS as a legitimate medical condition.

Jacobsson (2011) explored the impact of coeliac disease (CD) on the life experiences of 106 Swedish women with CD. As defined by Jacobsson, CD is "a chronic inflammation, with damage in the small intestine due to gluten presented in wheat, barley, and rye" (Jacobsson, 2011, p. 1), resulting in nutrient mal-absorption. Two scales of well-being, encompassing psychological general well-being and gastrointestinal symptom rating, were administered to women with CD at baseline and after a program intervention. In addition, a sub-section of participants were interviewed, from a narrative and phenomenological perspective, on their experiences of living with CD. Half of the women participating in the study participated in the intervention program, which was a ten-session educational program called the "Coeliac School" that utilized problem-based learning. In contrast to participants in the control group, participants in the "Coeliac School" reported improved outcomes in both psychological well-being and gastrointestinal symptomology at the end of the ten-week educational program. Jacobsson also reported three key findings in participants' narratives describing the phenomenon of living with coeliac disease. These were: (a) conflicting feelings of security versus insecurity across different situations; (b) conflicting feelings of control

versus loss of control; and (c) feelings of visibility and inclusion in contrast to feelings of invisibility and exclusion.

Discussion and Conclusion

The jury is still out regarding whether extant conceptual binary constructs of disability are adequate to articulate the lived experience of women with disabilities. Documentation of the experience of women with hidden (non-visible or invisible) disabilities is emergent (Stone, 2005; Sturge-Jacobs, 2002; Taylor, 2005). This preliminary review of the literature has illumined the significant issue of legitimacy—or more specifically, challenges to the very legitimacy of their disability—that women with non-visible disabilities must negotiate in their identity. As this review of the literature has shown, women with invisible impairments must grapple with the challenge of public ambivalence regarding the legitimacy of their disability, given its non-visible nature.

By completely excluding the notion of endogenous impairment, the social model of disability inadvertently may be undermining the legitimacy of women whose disabilities cannot easily be ascribed to a simple interaction between self and the environment. An entrenched hegemony of visibility, whereby a disability is publicly validated only by its apparent visibility, prominently appears as a challenge to identity negotiation for women with hidden disabilities (Gillespie, 1996; Stone, 2005; Sturge-Jacobs, 2002; Taylor, 2005; Valeras, 2010). This hegemony exists in mainstream society and, ironically, even within the disability subculture itself, thereby further marginalizing women with hidden disabilities (Lipson & Rogers, 2000; Roman, 2009). There thus remains a critical need for more studies documenting the experiences of women with hidden disabilities utilizing a variety of methods, including narratives and

phenomenology.

CHAPTER III

METHODOLOGY

Restatement of the Purpose of the Study

The purpose of this qualitative study was to explore the lived experiences of inclusion, marginalization, and exclusion in the lives of women who have a permanent, non-visible (hidden) disability. It also explored the corporeal dimensions, such as issues of embodiment, of the lived experiences for women with hidden disabilities. Finally, this phenomenologically-based study examined how women with non-visible, hidden disabilities articulate the meaning of living with an invisible disability.

Research Questions

This study investigated the following research questions:

1. What are the lived experiences of adult women who have a non-visible, hidden disability?
    a. What are the lived experiences of inclusion for women with hidden disabilities?
    b. What are the lived experiences of exclusion or marginalization for women with hidden disabilities?
    c. What are the corporeal dimensions (e.g., issues of embodiment) of lived experiences for women with hidden disabilities?
2. How do women with non-visible, hidden disabilities articulate the meaning of living with an invisible disability?

Research Design

This qualitative research study utilized a phenomenologically-based approach that incorporated in-depth interviewing, as described by Seidman (2006, p. ix). This particular method integrated in-depth, focused interviewing and life history interviewing. It was also grounded in fundamental assumptions of phenomenology with its focus upon lived experience (Seidman, 2006, p. 15; van Manen, 1990). A phenomenological lens allowed for the possibility of capturing the complex range of lived experience in the disability experience, including the conundrum of impairment (Hughes, 2008). As Hughes (2008) has written:

> Recourse to phenomenology embeds disability studies in an agentic theory of impairment in which the body is best understood in terms of embodiment… Phenomenology, which prioritizes the body of the mundane world of sensuous experience, presupposes a creative subject who is not reduced to a 'docile' outcome of the technique of modern social control. (p. 88)

In-depth interviewing with a phenomenological orientation provided the opportunity for the narrator, namely the individual who has lived that experience, to create meaning of the lived experience through language and storytelling (Seidman, 2006, pp. 7, 14). Regarding storytelling, Ricoeur (1992) articulated that "the art of storytelling is the art of exchanging *experiences*" (p. 164).

A primary purpose of phenomenological inquiry is understanding the very nature or essence, specifically the description of a phenomenon, as it pertains to lived experience (van Manen, 1990, p. 164). Regarding the nature of lived experience, van Manen observed:

> Every project of phenomenological inquiry is driven by a commitment of turning to an abiding concern…It is always a project of someone: a real person, who in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence. But while this

> recognition does not negate the plausibility of the insights gained from a specific piece of phenomenological work, it does reveal the scope and nature of the phenomenological project itself. A phenomenological description is always *one* interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially *richer* or *deeper* description. (p. 31)

A shared purpose of in-depth interviewing and empirical phenomenological research is to determine and understand the lived experience of another, along with the meaning ascribed to the experience by the individual who has lived it (Moustakas, 1994, p. 15; Seidman, 2006, p. 9).

Population

Participants included four adult women who have a permanent, non-visible disability, including chronic illness. Additional, essential criteria of participants comprised the following: (a) interest in understanding the nature and meaning of the central phenomenon that they have experienced, (b) willingness to participate in a series of in-depth interviews, (c) willingness to permit the researcher to digitally record and transcribe these interviews, and (d) willingness to grant the researcher permission to potentially publish de-identified data in a dissertation and other academic or professional publications (Moustakas, 1994, p. 107).

The researcher used purposive qualitative sampling to recruit four research participants within the United States. Purposeful qualitative sampling involved the intentional selection by the researcher of individuals to enhance the understanding of the phenomenon under inquiry (Creswell, 2008; Seidman, 2006). The type of purposeful qualitative sampling utilized was maximal variation sampling (Creswell, 2008, p. 215; Seidman, 2006, p. 52). Maximal variation sampling required the researcher to sample individuals or cases where there is a difference on a particular trait (Creswell, 2008). For

example, for the purposes of this study, the difference on a particular trait was the type of disability of prospective participants.

The researcher obtained access to the subject sample through the researcher's professional network of colleagues. This professional network comprised colleagues from the researcher's professional work as a speech-language pathologist, as well as from the researcher's volunteer work across different settings in past years. The researcher asked colleagues within this professional network to recommend individuals who met the criteria delineated above. The researcher then solicited participation from these potential subjects via initial email or phone contact, with follow-up face-to-face requests if in-person meetings were feasible. The number of these attempts at subject recruitment was limited to a maximum of three requests.

Group Profile of Participants

Group Profile

All four participants were graduates of four-year universities and colleges within the United States. Pseudonyms were used to protect participants' privacy and for purposes of confidentiality. Two participants had graduate degrees, including a master's degree and a doctorate. All were diagnosed with their respective conditions within the U.S., and all continued to reside within the continental U.S. in metropolitan, coastal areas in either urban or suburban settings. Two participants resided in northern California, and two resided on the East Coast of the U.S. All participants worked full-time. Linguistically, all participants were English-speaking, and none were from ethnic minority backgrounds.

Table 2

Individual Participants

Pseudonym	**Age (at time of Interview)**	**Diagnosed Condition**	**Age at Diagnosis**	**General Geographic Location of Residence**
Sam	43 y.o.	Addison's Disease (& Hypothyroidism)	26 y.o. (5 y.o.)	West Coast of the U.S.
Anna	39 y.o.	Multiple Sclerosis	24 y.o.	West Coast of the U.S.
Emily	28 y.o.	Stargardt's Dystrophy	15 y.o.	East Coast of the U.S.
Lynn	36 y.o.	Unexplained Infertility	33 y.o.	East Coast of the U.S.

Sam was a 43-year-old female who worked and resided on the West Coast of the United States. As a child, she was diagnosed with hypothyroidism. In her young adulthood and at the age of 26 years, she was also diagnosed with Addison's disease. Addison's disease is a rare, chronic disorder characterized by acute adrenal insufficiency (U.S. Department of Health and Human Services & National Endocrine and Metabolic Diseases Information Service (NEMDIS), 2013). This insufficiency results from the compromised ability of adrenal glands to produce two hormones, specifically cortisol and aldosterone (Johns Hopkins Medical Institutions : Autoimmune Disease Research Center, 2013). The condition may be life threatening without appropriate medical intervention (U.S. Department of Health and Human Services & National Endocrine and Metabolic Diseases Information Service (NEMDIS), 2013).

Anna was a 39-year-old female who resided and worked on the West Coast of the United States. She was diagnosed with multiple sclerosis at the age of 24 years. Multiple sclerosis is a chronic, immune-mediated, demyelinating disease that attacks one's central nervous system (Mayo Clinic, 2013). Frequency and severity of symptoms may be unpredictable and also variable across individuals (National Multiple Sclerosis Society, 2013).

Emily was a 28-year-old female who worked and resided on the East Coast of the United States. Emily was diagnosed with Stargardt's dystrophy at the age 15 years. Stargardt's dystrophy, also known as Stargardt macular degeneration, is a rare, heritable eye disorder and the most common type of juvenile macular degeneration (U.S. National Library of Medicine and National Institutes of Health, 2013). The condition principally affects the macula, resulting in progressive, central vision loss (Openshaw, Branham, & Heckenlively, 2008) The rate of progression of the disease varies across affected individuals.

Lynn was a 36-year-old female who resided and worked on the East Coast of the United States. She was diagnosed with unexplained infertility at the age of 33 years. Unexplained infertility describes a reproductive condition in which the cause of a couple's or individual's infertility cannot be attributable or identifiable to a specific etiology (Ray, Shah, Gudi, & Homburg, 2012; Resolve: The National Infertility Association, 2013).

Interviews

As detailed by Seidman (2006), the phenomenologically-based, in-depth interviewing model consisted of a series of three 90-minute interviews with each participant: (a) a first interview that centered around a focused life history of the

participant, (b) a second interview that focused upon the details of the experience and contemporary experience, and (c) a third interview that involved the participant's reflection on the meaning of her experience (pp. 17-19). Although rigid adherence to a priori interview questions is not optimal, the gestalt of an interview guide, including primary themes, was helpful for this beginning researcher (p. 92). To that end, some possible questions for each of the three interviews are articulated below. These questions are also included in Appendix B. It is also significant to note that there is not a one-to-one correspondence between the first, second, and third interviews and the order of the research questions.

The First Interview

The first interview of the three-part series explored the process that led the participant into the realm of living with a non-visible disability. The researcher used the following as a general guide:

> "Today, we will take some time to discuss your life experiences that led you to into the realm of disability, in particular the realm of a hidden disability. I would like you to take some time to retrace the steps in your life's journey that have led you to the point at which mainstream society began to formally identify you as a person with a disability (or a disabled person)."

1. Tell me the story of how you came to learn you had a non-visible disability.

Possible sub-questions:

a) When and how did you learn that you had a disability?

b) How did this discovery affect you?

c) What was the process of "formal diagnosis" and was it brief or extended in duration?

d) What challenges did you face during this period?

e) How did you cope with and overcome these challenges?

f) What were some unexpected sources of strength during this period?

g) If there were one to three words that you would use to describe this period, what would they be?

h) What aspects, incidents, and people intimately connected with this experience stand out for you?

i) What changes do you associate with this period/ experience?

i) What feelings were generated during this period?

ii) What thoughts stood out for you?

iii) What bodily changes or states were you aware of at this time?

If the participant has not yet brought this up, also consider exploring:

i) How did this experience affect significant others in your life?

ii) Were there particular individuals who influenced you during this period?

iii) Who were those who influenced you positively and how did they do so?

iv) Who were those who influenced you negatively and how did they do so?

v) Is there anything else that you would like to share before we close?

The Second Interview

The second interview explored the participant's contemporary experience of living with a hidden disability. The researcher used the following as a general guide:

"Today, we will explore your contemporary, present experience of living with an invisible disability. I would like for you to share with me as best you can what it is like

for you to live with a hidden disability."

1. Tell me the story of what it is like to live with a hidden disability. Please describe your present-day experience of living with a non-visible disability.

Possible sub-questions:

a) Please tell me about your daily experience of living with a hidden disability.

b) Please tell me a story that illustrates your daily experience of living with a hidden disability.

c) Please tell me the story of how your experience of living with a hidden disability has evolved over time.

i) What challenges have you faced?

ii) How did you overcome these challenges?

iii) Were there any epiphanies or turning points during your journey of living with a hidden disability?

d) Within the context of your experience of living with a hidden disability, please tell me about your relationships with others on a daily basis (e.g., family, friends, work colleagues, and others)

2. Is there anything else that you would like to share before we close?

The Third Interview

The primary focus of the third interview explored what it meant for the participant to live with a hidden disability. The researcher used the following as a general guide:

> "Today, in our last interview, we will explore what living with a hidden disability means to you. This is a reflection on the experience of living with a hidden disability. I would like for you to share with me as best you can what it means for you to live with a hidden disability."

1. In light of our last two conversations (interviews), how do you understand the experience of living with a hidden disability in your own life? What sense does it make to you? Or not?

2. What are your aspirations, expectations, and hopes regarding your future experience of living with a hidden disability?

3. Stepping back from your own personal story, what is your vision for the future of women who live with hidden disabilities?

4. Is there anything else that you would like to share before we close?

Validity

Seidman (2006) addressed the issue of generalizability, which is pertinent to issues of external validity for experimental or quasi-experimental studies and less pertinent for interview studies where randomness is not inherently applicable. From the perspective of Seidman, there are two alternatives to generalizability for the researcher-interviewer. The first is the discovery of connections among the experiences of those whom have been interviewed. The second is the opportunity for the reader to connect his or her story to those stories that are presented in the study from the in-depth interviews. Both alternatives are only possible if the researcher is able to "go to such depth in the interviews that surface considerations of representativeness and generalizability are replaced by a compelling evocation of an individual's experience" (p. 51).

The three-interview structure as articulated by Seidman (2006) had additional elements that further augmented validity. These elements included cross-checking for internal consistency of participants' shared stories over the course of one to three weeks.

In addition, validation of data was additionally ensured through review of all respective transcripts by participants (Moustakas, 1994, pp. 110-111).

Data Collection

Seidman's In-depth Interviewing Process

Data was collected following the detailed procedures outlined by Seidman (2006) regarding the three-interview structure for each participant. For each participant, interviews were conducted between three to ten days apart. This interval spacing between interviews allowed for processing and reflection on the part of both the researcher and the participant (p. 21). Interviews took place in private settings of the participant's choice to assure maximum privacy, confidentiality, and comfort. On the first day of meeting in-person with each participant, the researcher reviewed the informed consent form, as approved by the University of San Francisco's Institutional Review Board (IRB) for the Protection of Human Subjects. Each interview was a maximum of 90-minutes in duration.

All interviews were digitally recorded for future audio review and transcription after obtaining the consent of participants. In addition, all participants gave verbal consent to the use of an external transcriber for the recorded interviews. During the temporal interval between each of the three interviews for each participant, the researcher sent the recorded, de-identified audio file to an external transcriber, who was educated about the high level of confidentiality and privacy regarding the material to be transcribed. (Seidman, 2006, pp. 115-116).

Each participant had the opportunity to review written transcripts of all their interviews and to provide feedback. When possible in terms of the time interval between subsequent interviews, the researcher emailed a de-identified copy of the prior interview's transcript to the participant for her review and feedback in advance of the next interview. Two de-identified, hard copies of every transcript were also kept in single binders; these binders were kept in a secure file cabinet to which only the researcher had access.

Before the second and third interviews, the researcher reviewed the previous interview transcript with each participant. Key issues for review and feedback included the following: (a) additional clarifications for the researcher regarding the participant's narrative, (b) any corrections in the transcript that the participant felt necessary to make in light of potential inaccuracies in transcription and (c) any possible content areas that the participant did not want to include in the final write-up of results by the researcher.

Additionally, field notes were also an integral component of the data collection process. As defined by Saldana (2010), field notes are "the researcher's written documentation of participant observation, which may include the observer's personal and subjective responses to and interpretations of social action encountered" (p. 33). These field notes included pre-interview and post-interview reflections by the researcher regarding the process. As such, these field notes became fertile material for future cultivation and for the development of analytic memos during the later process of data analysis (p. 33). Field notes were kept separately from the raw interview data, specifically the interview transcripts.

Data Analysis

The researcher did not commence data analysis until the three-cycle interview process had been completed for each participant (Seidman, 2006, p. 113). Preliminary data analysis principally followed the procedures outlined by Seidman for studying, reducing, and analyzing the interview data. In addition, the use of analytic memos, as described by Saldana (2010), were also used during the analysis by the researcher. These analytic memos, which are different from field notes, captured "*anything* related to and significant about the coding or analysis of the data" (Saldana, 2010, p. 33). These analytic memos thus contained content pertaining to "future directions, unanswered questions, frustrations with the analysis, insightful connections, and anything about the researched and the researcher" (p. 33). The purpose of these analytic memos was to provide a means for additional documentation and reflection upon the following: the coding process, the choices made for coding, and emergent categories, subcategories, themes, concepts and patterns evolving from the data (p. 32).

Initial Reduction of the Data

The researcher followed the general guidelines for reducing the initial corpus of raw data, namely the discourse contained in the interview transcripts, as set forth by Seidman (2006). First, the researcher twice re-listened to all the recorded interviews of each of the participants. In the first audio review, the researcher listened to all the interviews in cycles across all participants (e.g., the first interview across all participants, followed by the second and third interviews across all participants). The researcher wrote down new impressions that arose during this first audio review process. In the second

audio review, the researcher solely listened to all the interviews, again in cycles, without taking any written notes.

The researcher then marked, via bracketing, passages of interest in the written transcripts as material for potential excerpts. The researcher followed the process of consecutively reading and marking each of the three interview transcripts for each participant, thereby attempting to keep the voices of each participant separate from one another in this preliminary coding.

Initial Analysis and Interpretation: Participant Profiles

Seidman (2006) proposed two means of reducing the data for further exploration, analysis, exegesis, and interpretation. These two means were the following: (a) creating profiles of individual participants and (b) marking passages in the text that are of interest, grouping these passages into categories, and inferring potential thematic connections among and within these categories (p. 119). Consistent with the first means, the researcher extracted all marked, bracketed excerpts from the transcripts of each participant following the initial reduction of the data. Criteria for the extraction of these excerpts was informed by potential relevance to the study's key research questions which address issues of inclusion, exclusion or marginalization, and meaning-making. From this extraction of relevant excerpts, the researcher then constructed a holistic profile of each participant, with the goal of privileging each participant's own voice through the use of the participant's own words (pp. 120-122).

Secondary Analysis and Interpretation: Material Feminism

Following the initial crafting of participant profiles, the researcher then performed a secondary diffractive analysis of these profiles using a material feminist lens to further

explore how images and portraits of women with invisible disabilities are produced in both material and non-material ways (Alaimo & Hekman, 2008b; Jackson & Mazzei, 2012). A diffractive analysis views data across "multiple, conceptual perspectives, a viewing that opens up and diffracts, rather than crystallizes, representation" (Jackson & Mazzei, 2012, p. ix). This diffractive analysis of each participant's profile focused upon material-discursive practices, specifically the potential intra-action of non-discursive material with the discursive, that were recounted in the narratives of each participant (Alaimo & Hekman, 2008a; Barad, 2008, pp. 140-141; Hekman, 2008). According to Jackson and Mazzei (2012), utilizing a material feminist theoretical lens in the process of analyzing qualitative data enables the following:

> It is the work of Karen Barad and others named as "new materialists" or "material feminists" to ask how our intra-action with other bodies (both human and non-human) produces subjectivities and performative enactments not previously thought…This is to think of *knowing in being* that is not merely a re-insertion of the material, nor a privileging of the material, but a shaking up of the privileging of the discursive in postmodern thought without a re-centering of the material that preceded the linguistic turn. (p. 9)

The researcher also drew upon the analytic memos documented during the data collection process, including the researcher's pre-interview and post-interview reflections, as additional material to consider in this secondary analysis. The final stage of interpretation involved the researcher's reflection upon the research experience and what it meant to her (Seidman, 2006, p. 129).

Delimitations and Limitations

There are a number of delimitations of this study. First, only women were included as participants. Second, participants were women whose disabilities were not

visible. Third, participants were those whose disabilities have been acquired during or after late adolescence.

This study may also have three primary limitations. First, due to the study's very small sample size, results cannot be generalized to the broader demographic of all women with disabilities. Second, the study did not control for decoupling the dual variables of gender and disability. Consequently, it was not easily ascertainable from the study's results to determine whether any potential experience(s) with discrimination could be attributable to female gender versus disability or to a combination of both factors. Finally, the interview questions may have reflected an unconscious, unintentional bias of able-ism, as the researcher has ostensibly been able-bodied. The researcher attempted to minimize this potential bias by actively documenting, through writing, prospective biases that she may have had prior to conducting all interviews with each of the participants.

Researcher Background

In an attempt to potentially disaggregate areas where self and topic may become conflated, I wish to disclose some relevant information about my background (Peshkin, 1988). My interest in this research topic has germinated from my clinical work as a speech-language pathologist and from personal experiences with colleagues and friends who have sojourned into the realm of the disabled, moving from an initial position of able-ism. As a clinician, I have worked with children and adults with speech and language disorders. These communication challenges frequently co-existed with additional hidden (non-visible) disabilities, including traumatic brain injury, autism, stroke, and dysphagia. Notwithstanding these disabilities, my clients appeared "normal" to friends and family in terms of visible, physical appearance. This appearance of

normalcy ironically strengthened the level of denial by friends and family members regarding my clients' difficulties, arising from their non-apparent disability, in negotiating quotidian activities and challenges of everyday life.

I have, historically, been ostensibly "able-bodied" except for established myopia with astigmatism. Although this myopia is not severe enough to be considered blindness in legal terms, my vision is severely compromised without prescription lenses or glasses. In addition, I am also experiencing increased presbyopia where the eye has a progressively diminished ability to focus on proximal objects, secondary to increasing age. From one perspective then, namely being without prescription lenses or glasses, one could argue that I have significant visual impairments affecting optimal execution of activities of daily living, including reading, writing, cooking, and driving. My visual impairments are only visible to others when I wear my prescription glasses; my glasses thus function as an indexical sign of my compromised visual acuity (Siebers, 2011, p. 109).

In the past five years, I have become more involved, both within and outside of my profession of speech-language-pathology, with advocacy and education projects to further integrate the dialogue of disability rights into the broader rubric of international human rights. My research continues to inform my activism and professional, collaborative projects. Reciprocally, my activism provides a critical, relevant context for my research and scholarship.

CHAPTER IV

FINDINGS

Overview of the Chapter

Restatement of the Purpose of the Study

The purpose of this qualitative study was to explore the lived experiences of inclusion, marginalization, and exclusion in the lives of women who have a permanent, non-visible (hidden) disability. It also explored the corporeal dimensions, such as issues of embodiment, of the lived experiences for women with hidden disabilities. Finally, this phenomenologically-based study examined how women with non-visible, hidden disabilities articulate the meaning of living with an invisible disability.

Research Questions

This study investigated the following research questions:

1. What are the lived experiences of adult women who have a non-visible, hidden disability?

    a. What are the lived experiences of inclusion for women with hidden disabilities?

    d. What are the lived experiences of exclusion or marginalization for women with hidden disabilities?

    e. What are the corporeal dimensions (e.g., issues of embodiment) of lived experiences for women with hidden disabilities?

2. How do women with non-visible, hidden disabilities articulate the meaning of living with an invisible disability?

Organization of the Chapter

This chapter presents the results from the three in-depth interviews with each of the study's four participants. The two primary research questions, with respective sub-components, of the research study provide the principal framework around which the chapter is organized. Following a brief group profile of participants, primary results are presented as they pertain to each research question.

In order to privilege the voices of the study's participants, excerpts from the interviews are presented, rather than paraphrasing. Interview quotations are referenced using a common format, which is the following: Participant #, Interview #, line number(s) in the interview transcript. In addition, unless otherwise noted, for each participant, excerpts are typically presented in chronological order within a particular section in order to the preserve the integrity of the narrative and to obviate the phenomenon of *in media res.*

Results from the researcher's secondary analysis and interpretation using a material feminist lens are also presented at the end of each section. These brief sections, entitled "Material Interactions," concisely highlight issues of intra-action of non-discursive material, such as social, economic, political, technological, and biological factors, with the discursive factors recounted in participants' narratives. Finally, the chapter closes with a brief chapter summary.

Research Question #1(a): Results

Research Question #1 (a): What are the lived experiences of inclusion for women with hidden disabilities?

Results encompass data from participants' narratives culled from all three in-depth interviews, with primary data being drawn from the first and second interviews. Results are bifurcated into experiences of inclusion during the initial period during which participants were undergoing and managing the initial diagnosis of their respective conditions, in comparison to inclusion experienced during the course of daily, contemporary living after diagnosis.

Inclusion during the Diagnostic Period

Experiences of inclusion during the diagnostic period comprised support from family, friends, and some exceptional colleagues at work. Participants all spoke to the positive, supportive role that certain individuals played in the challenging period in their lives when they were undergoing diagnosis for their respective conditions.

Support from Others

Sam received support during the non-linear process of her diagnosis of Addison's Disease from her friends, her boyfriend, and her family. In one example, Sam's friend, who was studying to be a pharmacist, advocated effectively on her behalf at a critical time in the hospital right after her initial diagnosis.

> When I was in the hospital and finally diagnosed, they were trying desperately while I was super dehydrated and super thin and they were trying to rehydrate me and gave me way too much saline and way too much electrolytes and caused edema. Luckily, they caught it and in fact a good friend of mine was getting her Pharmacology degree at the time and actually asked them why they seemed to be doing this really quickly and it seems like it could be potentially dangerous. (1.1, 153-158)

Sam also experienced more support from the medical establishment once a formal diagnosis of Addison's Disease had been obtained. With this new support came a feeling of relief and validation:

> Relieved. I knew I could get healthy. I knew that I could be believed. I knew that I could go back to normality. (1.1, 249-250)

> It was relief and a sense of well-being, a sense of clarity, really. (1.1, 362)

> Frankly, at that point, I had a whole slew of doctors. I had a doctor who treated edema. I had a doctor who treated me as an endocrinologist. I had a gazillion doctors so I felt much better and I was able to fire the psychologist so I could quit with that frustration. (1.1, 633-636)

In addition, her boyfriend, friends, and parents were able to provide more concrete support once a diagnosis was obtained as they finally knew "what they are dealing with:"

> …they were super helpful once it was diagnosed because everyone understands what they are dealing with. (1.1, 622-623)

Anna received heartening support from her sister and from a supportive colleague at work. In her words, her sister was an ideal friend offering empathic support:

> She is the perfect kind of friend because she can relate, because she will have really bad headaches and stuff, so it is not a chronic disease like mine is but she can relate the idea to some parts of her life and she doesn't try to assume. She will ask me questions about it and not try to stay away. She was really good and she did not worry for own self. Or, if she did, I did not hear it. (2.1, 236-240)

Of a particularly supportive colleague at work, Anna observed the following of how he provided strength to her:

> E. was really good with the sympathy and the work and then helping with priorities and the value of your health, of your sanity, of the level of stress. He was saying that those are the important things in life—that I should have a good life and feel good every day. So, he was really good with that and then he was sympathetic to the disease stuff. He was not obsessively condescending, but he was there as a source of strength. (2.1, 325-329)

Anna also received support from her physician at the point of diagnosis and after she was diagnosed with multiple sclerosis (MS):

> The doctor was really helpful when she gave the diagnosis. She spent a lot of time telling me: This is what it is. This is what to expect. And she was very reassuring. All my doctors have been that way. They would say that I may have certain things happen, but that I could lead a normal life. I don't have to do a special diet. (2.1, 477-480)

At the time that Emily received the unexpected diagnosis of Stargardt's Dystrophy, Emily already had a strong social support network. This network included her mother, a network of friends, and the social support from her active involvement with school choir:

> …so pre-diagnosis I would have to say I was really close with my mom. I really considered her my best friend. I think also being the oldest, I think that is natural. I had a really good friend circle. (3.1, 221-223)

> I very much am heavily into choir and especially that sophomore year I had auditioned and had gotten into the top choir at the school and that was my life. (3.1, 228-229)

> I was very shy and I was this girl who never really spoke and I think during that year, and I got so frustrated because I knew that I was so much more and that I could—but I was funny and so that year, I really came out of my shell and I found that I had a great group of friends that really knew me for who I was and they saw the potential there. It was fun. I just loved it. (3.1, 242-245)

> So those were really positive influences on my life. (3.1, 263)

Emily observed that her mother played an important role in helping her develop initial self-advocacy skills during the initial months post-diagnosis, which also coincided with her junior year in high school:

> So by the end of the year it got better. By the end of the year I had started to learn some self-advocacy stuff. My mom was a big support in that. (3.1, 336-338)

Lynn recalled the unique support she received from a particularly supportive physician during the period when she was navigating the challenging, shifting terrain of a diagnosis of unexplained fertility, along with the rigors of assisted reproductive technology (ART) treatments:

> She [the physician] called herself and said how excited that she was for us. She was so great. Even though at the end of the day, we ended up in the same place, it still felt like she helped me finally realize where we were. For the first time I felt like I could see, *Oh, this is what we are doing. This is what we have to do if we want to get pregnant in the next couple of years on our own.* By that I just mean with our own biological ingredients. Because there are a lot of other options but if we want to do this with our stuff, this is what we are going to have to do. At the time it was hard to hear but it was very helpful because after that, I think I became just a little bit more realistic. (4.1, 389-396)

In addition, Lynn also found respite in receiving treatment via Traditional Chinese Medicine following the stress of two early miscarriages:

> For some reason, the Chinese medicine, it supported that process because I think it was helping me feel physically better at the same time. (4.1, 805-806)

> So, aside from exhaustion and whatever two miscarriages will do to you physically, I was walking around like I was a zombie. So, she brought me back to myself and it was amazing. It just helped so much and also having the time that was cut out for me to go and do this thing. It felt really amazing and it felt like it was helping and it just made a big difference for me. (4.1, 427-430)

Daily, Contemporary Experiences of Inclusion

Participants spoke of experiences of inclusion while living with the diagnosed condition over time. Ongoing, empathic support from family, friends, understanding health professionals, and some colleagues at work provided a welcome sense of inclusion. Finally and notably, participants also created a sense of inclusion for themselves via self-advocacy and through a process of acceptance and integration of their condition into their own identity.

Support from Others

Anna received pragmatic support from her future fiancé (now husband). This support was pivotal in changing her perspective about managing her symptoms and condition in terms of simple logistics.

> So, what I remember is actually is dear B., he gets like the prime spot in life, when we met, I had to tell him because I was falling in love with him, so I had to tell him about the MS. (2.2, 145-146)

> I remember when I told him and I really think that this is a moment that changed everything. He said, "Okay." At that time, I was really having episodes. I was having symptoms. I was not happy. He said, "Well that's just logistics then**.** We'll figure it out." Ever since then, that is how he sees it and now that is how I see. It is just logistics. We can figure the rest out, or we can figure it out. (2.2, 165-169)

> It was just like this logistics thing—like, okay, well, this is how we need to do it. (2.2, 244-245)

> …it was more of, like: I have brown hair. It was just more of a factor or something like that. Like, if you get headaches then you stay out of the sun or something like that. It was a just matter-of-fact thing that could be dealt with just as a logistic, and mine would be different than yours… (2.2, 265-268)

In her daily experience of living with her disability during college and post-college, Emily found that her family, her friends, her boyfriend, and evolving technology all contributed a positive influence in her determination to live independently. Emily made this observation about her college years:

> Living on a daily basis was a little scary back then; this is where my family came into play, and my mom was such a great supporter for me. I would call her three times a day and half of the time I would be in tears. (3.2, 23-25)

> I never felt uncomfortable talking about it back then. The girls in my hall are my best friends to this day. I got very, very lucky. (3.2, 81-82)

Her insights about her support system today include the positive role of technology in building bridges to inclusion:

> I have been very lucky to have a great support system and grow up in the age of technology. That is where the shift is going to come because the generation below me didn't have that experience because they didn't grow up with the technology or the acceptance of the professional world that I have been experiencing today. (3.2, 190-193)

> I honestly can say I don't know where I would be or how I would be where I am today, without my family, without my friends from freshman year and my best gal friend that I still have from High School and especially my boyfriend today. They

> push me but in a very compassionate way and they haven't let me become complacent or inactive. They know how much my independence means to me so they let me have it. (3.2, 673-678)

> I feel very lucky to have the support system that I have to grow up in the age of technology. (3.2, 683-684)

Emily has also found support in her current work environment from a co-worker who was particularly sensitive in remembering the accommodations she needs in the professional setting.

> …so if I am sitting in a meeting and we are going over something and I am looking over a coworker's shoulder on a database or something on their computer screen, I have one coworker who will automatically zoom in on it for me to see. I don't even have to ask him. He just has this awareness that he remembers I probably can't see his computer screen and he just automatically problem-solves it, which is nice. Even if he is doing it and it doesn't really help, he is still aware of it and I don't feel like I have to remind him again. (3.2, 248-253)

In the course of riding waves of uncertainty related to revised diagnoses of unexplained infertility and concomitant Assisted Reproductive Technology (ART) as intervention, Lynn received support from her husband, her mother, her acupuncturist and practitioner of Traditional Chinese Medicine, as well as her diverse social network of friends. Regarding the empathy of her husband, Lynn observed the following:

> He really felt it even though it was my body that was undergoing these various gymnastics. (4.2, 347-348)

The support from her mother and empathetic friends was particularly helpful in helping her navigate the challenging terrain of coming to terms with a constantly shifting diagnosis of unexplained fertility. When she disclosed to her mother her diagnosis and treatment protocol, Lynn found her mother to be a significant source of socio-emotional support, alleviating an unconscious sense of stigma that she had been bearing unwittingly:

> I ended up telling my mom everything and it was really helpful. Even though she basically said *I know you and I know that you aren't going to want to talk about this all of the time, so you just tell me when you want to talk about it. I am not going to ask you about it and just know that whatever you decide to do, we are totally happy with.* For me, it took this weight off my shoulders because I felt like I was living in this hidden world where not even my parents knew that we had been doing this and it was part of the reason why I was being so private about it was because it was not shameful but it didn't feel accepted and it didn't feel like something that people would understand. (4.1, 451-458)

In addition to the support from her husband and mother, Lynn acknowledged the diversity of her social network, including friends from her profession as a researcher in public health, as a unique source of strength when she was navigating the novel path outside the socially normative one that her diagnosis imposed:

> It also gives me a big appreciation for people who are struggling with this without open-minded friends and without families who get science and medicine and just want to be supportive because it was so hard for us. I can't even imagine going through this without that safety net or without that social network that was there for us. (4.1, 780-784)

> For me, I am really grateful to have such a diverse social network… 4.2, 617)

> For the most part, we had that in place in public health. It attracts a non-traditional type of person anyway and so there is definitely a lot of people to fit the non-traditional mold. (4.2, 621-623)

In particular, a friend who had volitionally chosen to be childless by choice provided Lynn with invaluable compassionate understanding and support:

> …the "childless by choice" woman has been the most empathic and has just been there for us. She is someone who is amazing at connecting with difficult situations in life and so she, even though it is not her choice, she know that it is hard for us and she has been super supportive. (4.1, 561-564)

> So, it was just this perfect mix of *We can go there if you want but we don't have to. We can still just be the same that we were. But, if you want to go there, I will go there with you.* That was just really helpful to have someone like that who is willing to do the emotional work and not shy away from it**.** (4.1, 610-613)

Lynn also discovered that her weekly sessions with an acupuncturist were particularly helpful in providing objective insights from a holistic perspective uniquely separate from Western medicine:

> Maybe that was going to acupuncture and having someone that I was seeing weekly and talking with about it and it really helped… (4.2, 466-468)

> She is just so great about addressing the whole person and part of that whole person is your mental health and so we did a lot of talking and I think that it made a big difference for me in that journey and coming to figure out how to cope. (4.2, 475-477)

> And she was so great because she was just there to support whatever decision that I make. She didn't have a certain path in mind but every single other person in my life did and so that was really great and I do think that my husband could have benefited from having someone totally objective to just talk it out with. (4.2, 482-485)

Changing Exclusion into Inclusion via Self-Advocacy

All four participants shared contexts in which they applied their emergent self-advocacy skills to novel situations in order to transform potential experiences of marginalization or exclusion into inclusion.

In Sam's case, it was essential for her to bring up with others her critical need for an available vial of emergency medication to obviate an Addisonian crisis in certain situations. An Addisonian crisis, which is also known as acute adrenal insufficiency, can be life-threatening due to the body's inability to produce cortisol under conditions of stress and is considered a medical emergency:

> Definitely in the background where it does come into play in terms of friendships it is on the one hand minor and on the other hand sort of a big ask. (1.1, 646-647)

> So, in addition to the daily medication, I have also got a vial of emergency medication for the purpose of what is known as an Addisonian Crisis. So, that could be everything from, it could be brought on by everything from, severe allergic reaction to getting into a car accident, to some sort of trauma. (1.1, 647-650)

> So, when I travel abroad, I have to bring the vial with me and so depending on who I travel with, they need to know what to do. That is a lot to ask. (1.1, 650-652)

> It involves a needle and a syringe and it could be life-threatening. Just asking someone to be aware of it is sometimes even a lot. Obviously when you are in the U.S., it is a little different but when I travel abroad with people, it is an ask. (1.1, 658-660)

Sam also spoke of the paramount importance of self-managing her illness and self-managing her medical team in light of the rarity of Addison's disease:

> We spoke a little bit last time about the need for discipline and the need to be sharp and it was a learning process for me to realize that doctors are not God and, at some point, I had to manage my own illness. (1.3, 17-19)

> There was a learning curve and once I learned it, I learned how to say no to the psychologist that we talked about who was at my first hospital visit and also to manage two different endocrinologists and figure out which one [of two the endocrinologists] it made sense to follow the advice of… (1.3, 19-22)

> You have to manage the disease. You cannot rely on the doctors to do it. (1.3, 264-265)

Anna raised the issue of information management, particularly disclosure of her condition of multiple sclerosis to selected individuals, as a means of managing and overcoming her condition in her daily life:

> Other ways to overcome—well this doesn't really make sense really—but I think that part of the managing and overcoming has been being willing to tell people close to me. Both so I can get the emotional support that comes with friendship and then so that it is understood why I might be doing something that I am doing. (2.2, 695-698)

> Telling more people has been good and managing more like you said, just being more careful and more respectful, I guess, of my own self. You know, taking myself seriously and not beating myself up, not trying to pretend that it is not happening. (2.2, 705-707)

Anna also highlighted self-care, including the confidence to actively take care of her needs, as an important component of self-advocacy:

> Just taking care of myself. So, that is sort of the time of everybody knows it but it is invisible, but it is happening and how is it to be sitting somewhere in total pain and everybody else is fine and I am sitting there feeling: Oh my goodness, I am going to die if I cannot get out of this car! Just feeling so very miserable. (2.2, 321-324)

> It does feel very—empowering isn't quite the word—but, this is what I need and I am going to not worry what I think everybody thinks I should be doing because I really need to sit down right now because I don't want to trip. (2.2 455-457)

Emily shared examples of her growing self-advocacy skills during high school and college:

> By senior year of High School, I began asking for additional time on exams so I would have them given to me at a different location. (3.1, 393-394)

Of her time in college, Emily shared a number of examples of how she advocated for herself in academic and social settings. A few of these examples follow:

> It was also a big deal for me to have meetings one-on-one with my teacher before—I would walk into the classroom on the first day of class—I would have to walk down and introduce myself to my teacher, shake hands with my teacher and I would say, "Hi. My name is Emily. I am legally blind and I am going to be in your class for the semester and I need to set up a time for us to meet and talk about the accommodations that I need, your responsibilities as a teacher and my responsibilities as a student." We would do that and then there was this contract that we would fill out. (3.2, 34-39)

> …but it was basically all on me. It got to be normal. It got to be part of my normal routine every semester and because I had an invisible disability, during my freshman year, I also had a choice whether I told people about it or not. (3.2, 48-50)

> So, I remember in the first couple of weeks—I was living in a single room at the time—because I didn't have a roommate I didn't have that immediate link to other girls in my dorm room. I remember that I said *I am not going to sit in my room and isolate myself.* So, I walked down into the hall and said, "Hey, my name is Emily. I live in the single down at the hall, but I am really not antisocial like the other singles" (because they were all upper classmen…) (3.2, 50-55)

Emily graduated with a bachelor's degree in Animal Science, with a minor in Equine Science and Agribusiness in light of her long-term aspirations to become a

veterinarian. Upon her graduation from college, Emily had to confront an unsettling reality:

> So, I graduated and when I graduated from college I was legally blind with a degree that I really, I could use, but I had come to terms with the fact that it wasn't where I was meant to be in life. (3.1, 458-460)
>
> I had to do some serious soul-searching that I had to find a career now and I am still visually impaired. (3.1, 476-477)
>
> That is the real point—that I had to accept my disability. (3.1, 477)

In light of coming to terms with her disability after graduating from college, Emily began to take charge of shaping her future through three pivotal actions: (a) volunteering two weeks overseas in Asia to work in an elephant sanctuary (3.1, 619-621) to use her major; (b) connecting with the National Federation for the Blind and completing a job-readiness course for persons with visual impairments; and (c) moving overseas to complete a one-year internship in Europe at an organization that focuses on social change, specifically changing the way members of society, business, and government perceive persons with disabilities. Regarding her experience of living and working overseas on her own at This Great Org, Emily shared the following insights. These experiences overseas further shaped her job and career search trajectory upon her eventual return to the U.S.:

> It was great. I found my independence in every possible way of the word. (3.1, 723)
>
> I hadn't done a lot of research or work in the area of disability besides my own personal experience, so being able to look at it from a lens through how businesses accommodate, how different cultures accommodate, I didn't really have all of that experience to compare it to coming from the U.S., but it was helpful to see the value proposition behind disability in terms of business and I think that informed me a lot on coming back to the US and going through the job search is being comfortable and confident enough to say, "I have a disability and if you can't deal with it, that's your loss," in so many words, and recognizing that

> good businesses should be inclusive and should be open-minded enough to not create that barrier for talent. (3.1, 776-773)

> Other take aways from This Great Org I think were: learning how to accommodate myself in an office environment. (3.1, 778-779)

> Other take aways was [sic] I worked with a variety of people who had a variety of different disabilities through This Great Org. It wasn't just all visually impaired disabilities. (3.1, 783-785)

From the insights and skills she learned working overseas, Emily found that pro-active self-advocacy in her current work environment has been helpful in communicating necessary accommodations for her visual impairment:

> What I have found that has been useful is that the more and more that I request accommodations and am vocal about it, I think that helps them feel like they have a safe space to come back with more questions. (3.2, 467-469)

> I gave him a list of couple of examples of how I accommodate myself. For PowerPoint presentations, I can zoom in on my iPad and follow along that way. It created the space for that exchange which I am finding very helpful because I feel like people at my current organization are not going to ask questions unless I breach the topic first. (3.2, 479-483)

Similar to Emily, Lynn also found herself educating others about her condition of unexplained infertility:

> I found myself all along the way doing a lot of educating because I think it is really interesting just about what it meant and what the implications were. (4.1, 74-77)

Lynn also discovered dialogue to be an effective means to move from a liminal space of marginalization into inclusion, minimizing a sense of stigma:

> It just felt like this huge relief and a lot of it was because I had taken it from being invisible to making it more visible. (4.1, 815-816)

> I had geared myself up to do that and I started talking about it and all of this was happening around the same time where as I talked about it, it just made it more okay. It made it something that I could deal with. (4.1, 816-818)

As Lynn observed, the dialogic process allowed for the sharing of experiences via storytelling. Through this process of open experience sharing, Lynn discovered that her sense of isolation decreased, while her sense of empowerment increased through shared solidarity with others who had similar stories:

> It felt less stigmatized because—this is always the case with stigma right?—the more that you talk about something, the more you hear from other people that they have also had a hard time and what their story was like. So, when you open yourself up to it, then you actually get that relief of feeling like you aren't on your own and this isn't something that you are dealing with by yourself, in isolation. Other people have also struggled with this and so therefore you feel less abnormal and less like you are not like everybody else. That helped so much. For me to be able to go into it saying, "I'm okay. I am going to be okay even if this doesn't work." (4.1, 822-828)

Lynn spoke to the importance of pro-actively choosing those individuals who could be members of her community of support. These individuals comprised those who have chosen not to follow the mainstream path of normative, sociocultural expectations for social roles.

> There were always going to be—whether it be people who were just not going to take the path in the first place, like my child free friend, or lots of single friends, or gay couples who don't want to have babies, and so surrounding ourselves with those people really helped too. It was a reminder that, just because X% of the population is down that road, it doesn't mean that we don't have a completely legitimate other place to be and to have connections with people that supersede family. (4.2, 607-612)

In addition, Lynn also raised the affirming role that a community of insiders has played in her journey with infertility. These insiders, namely those "in the club" (4.3, 61), were also women who had shared a similar set of challenges in the landscape of fertility:

> In that way, it is interesting because you see that with other kinds of disability where there is an in group and an out group and I feel like I have lived that experience now. There is the sisterhood of women who have gone this route and it

> is very different. The way we talk about reproduction is very different than the mainstream, normal way people talk about it. (4.3, 50-53)
>
> It is who chooses to let you in on the fact that they are also in the club. (4.3, 61)
>
> …it is interesting even across that spectrum that by opening up myself, I open that door for other people to share with me what they have gone through. So, it is a really funny thing if you don't know that about someone and you share what you are doing and then you hear that they have been in the position, then all of the sudden you are bonded together in this battle, this war. It is not quite a battle; it is more of a war. (4.3, 66-71) It is a cause. (4.3, 75)
>
> It was interesting because you wouldn't know this about someone unless you had a really intimate conversation with them. It is one of the most private topics. I have gotten really good about picking up on the way things are said or a certain look when someone else makes a comment and it is almost like I now have this sense about me. It is almost like I now have this sensor. (4.3, 82-85)
>
> So, I think it is in these conversations that we identify who is in the "in" group. (4.3, 107-108)

Commenting upon the invisibility of her condition, Lynn observed that detection involves sensitivity, including the ability to decode both verbal and non-verbal communication:

> Yeah, there is no kind of marker or there is no external thing that you are showing the world that signifies that you are going through this or even that you've embarked on this journey or are in the thick of it. So, in that way, you almost have to be able to really decode what people say, how they say it, and how their facial expressions are geared towards other people's comments. You have ultra sensitivity and then you are able to make those connections and it is really amazing. It is almost like you have another sense. (4.3, 112-117)

Passing

Each of the participants addressed how the invisibility of their respective conditions facilitated some sense of inclusion in light of being able to "pass" as able-bodied. In their professional work, three out of four of the participants elected not to disclose to their employers or work colleagues any information about their diagnosed conditions or disability. In Sam's case, she has chosen not to divulge information about

Addison's disease in her professional life, except for instances of travel as noted previously when disclosure is indeed critically relevant:

> This no one would ever know about unless you told them. (1.1, 346)
>
> There is no need to disclose. It is not relevant in most situations (1.1, 675)

Anna also has selected the route of non-disclosure about multiple sclerosis in her current work setting, after having had a negative experience following disclosure of her condition in her previous jobs:

> No one knows. (2.2, 32)
>
> Before this, I did end up telling my boss/coworker and then she felt offended that I hadn't told her sooner which is sort of like: Why didn't you tell me? Did you not think that you could trust me? Was it something that I did? (2.2, 32-34)

Anna held that it became important to disclose information about one's condition if needing accommodations and now felt more comfortable in her current work environment to express such needs if they should arise:

> Yeah, I mean, it was like, this is a work relationship, I don't have to tell you these personal things and it is really irrelevant and so it is just much nicer not having to have that come up. I read a lot of things about it, like when you should disclose, and I think you should disclose when you need accommodations but also some of these things say that you should disclose in case something is going to come up and you may want to let HR know and all of that. I don't have any proper HR person to tell. (2.2, 564-569)
>
> Now I feel a lot safer if I should need to ask for something or do something. I am a little worried with this new medication and how it is going to make me feel. So, am I going to have sick time? Do I just take it? Do I tell? (2.2, 591-593)
>
> I feel like they will be supportive. It is a lot of guys that I work with now and I don't know, they are just way lower maintenance. They are engineers. I feel like from them or from my supervisor woman or from the department, I feel like they would do whatever I would need and I hope that I don't need to tell them first. (2.2, 622-626)

In contrast, Emily has chosen to self-disclose information about her diagnosis of Stargardt's Dystrophy during job interviews and in her employment settings:

> …having the experience of college and self-advocacy, reaching out to those peer networks of peers who are blind, it helped me see that I would rather (and this plays into having an invisible disability) someone know that I am visually impaired and have that awareness and change their mindset (3.1, 478-480)

> I think where I really started to see the necessity behind that is going through job interviews with a disability because I really do have choice whether I disclose or not. (3.1, 497-499)

Emily expanded upon how and why she discloses information about her disability during a job interview:

> I do have a choice whether or not I want to disclose in the selection process and so usually if it comes up naturally, I disclose, but if we get to the end of the interview and to questions and they say, "Do you have any questions?" Then, I will disclose and say, "Actually something that I haven't disclosed yet, but I want to take this time to, is that I am actually visually impaired, I am legally blind." (3.1, 504-508)

> I go into this whole thing about how this experience has give me self-advocacy skills and communication skills and I list all of these things and how I turn it back into a positive and I wrap it up in a nice little bow for them to remember. (3.1, 504-510)

> But I believe that it is something who has made me who I am today and it has given me great communications skills and leadership skills and (depending on which job I am applying for that is how I select what skills I want to showcase). (3.1, 515-518)

Emily acknowledged that she could be treading into "dangerous territory (3.1, 559) in divulging information about her visual impairment during employment interviews, but her rationale for doing so is that "knowledge breeds understanding" (3.1, 560):

> It is kind of a dangerous territory to tread, especially in a job interview, because if you open it up for questioning—I open it up for questions because I think that knowledge breeds understanding and lessens the fear around it. (3.1, 559- 561)

Similar to Sam and Anna, Lynn has also chosen not to self-disclose about her diagnosis of unexplained infertility in her professional work as a researcher. Regarding her decision, Lynn elaborated thus, expressing that work became a welcome respite from the challenges of managing her condition in other aspects of her life:

> I was able to negotiate that time well because of that but also because I felt strongly about trying to compartmentalize it. What was happening to me personally I would try to keep separate from my work because my work ended up being a place of respite and it was nice to go to a place where no one knew what was going on and I could just lose myself in my work and forget about it all. (4.1, 212-216)

> I ended up not telling him [my mentor] and I ended up being very happy with that decision because I am person who isn't comfortable with mixing work and life stuff so much. (4.1, 246-247)

Inclusion Arising from Material Interactions

As articulated in Chapter 1, material interactions encompass both interactions and intra-actions between bodies as corporeal embodiments in conjunction with broader, non-discursive, external material. This material includes socioeconomic, psychological, and cultural factors. In the 21st century, technology may also be a significant material factor impacting embodied beings.

The role of technology surfaced in the narratives of Emily and Lynn as being an important factor in cultivating their sense of inclusion. Emily expressed the transformative role that technology has played in living with her disability. Such technology included accessibility options and applications on smartphones:

> Then Steve Jobs came out with this amazing technology called Voice Over where he made touch screen accessible to people who are blind which is just absolutely amazing. I would be able to use a cell phone but not the way that a person who has 20/20 vision would be able. I would not have wanted to grow up 20 years earlier. (3.2, 685-688)

> I have this portable video magnifier called "The Amigo." It is awesome. I love it. It has changed my life. (3.3, 172-173)

> So, I think technology is a good—it creates an instance where I can tell people about it, but it is also because they have either initiated the curiosity factor so it is not about the fact that I am visually impaired. It is more like, look at what cool toys I get to play with because I am visually impaired. (3.3, 180-183)

> I don't anticipate losing my color vision, but there are color sensory apps. It goes on and on and on. It is really neat—which also helps with the long-term confidence level that as my vision deteriorates that I know there will be other ways to do things because technology is just constantly evolving and if I have found ways to do things now, I am sure I will find new ways of doing things in the future and having technology there continually advancing and keeping up is a great reassurance. It bodes well for self-reassurance and confidence going forward. (3.3, 216-222)

Lynn noted that the range of different options through assisted reproductive technology (ART) permitted a number of potential solutions for creating a family beyond adoption:

> I can still have a family even if it is not through my own biological material. There are other ways that this can happen and it doesn't need to just define the path that we are going to be on. We are not going to settle for infertile, no kids. We can be infertile and have kids. That just felt like a huge revelation. (4.1, 830-835)

Lynn further observed it was a process of acceptance; this process involved learning to separate the concept of pregnancy from the concept of creating a family in order to consider all available options for having a family:

> It was all a process, the comparisons to other people and the trying all of these funny things to make it work; it was all leading up to the acceptance of where we are at. This is the boat we are in and this is something that we can't necessarily control and being okay with that and getting to the point of acceptance and figuring out other ways that would solve the problem and make me feel like we could still at the end of it all have a family and letting go of the obsession of getting pregnant because it wasn't necessarily solving the particular problem. It was like disconnecting pregnancy from having a family. Probably unlike other disabilities, having that alternative route certainly felt really reassuring and takes away some of the uncertainty that it would never happen. Yes, it is difficult. It is not easy. You can't just got to a store and adopt a baby, but it is do-

> able, it is possible, and we know people who have done it. It is definitely an option. (4.2, 118-129)
>
> Having the options and knowing that if we wanted to we could pursue donor eggs and donor whatever and that would potentially also help. Yes, we wouldn't be able to do it ourselves, but we would still end up with a child that we would love and it wouldn't even be something we would think about, that it wasn't our own biological child. (4.2, 122-136)

In addition to the increased range of potential possibilities for creating a family through ART, the state in which Lynn and her husband resided requires insurance companies to cover ART up to a number of intervention cycles; thus, material support for treatment was not an undue financial onus for Lynn:

> It is awesome and we feel super blessed that financial considerations were not a part of this story at all for us because everything was covered by insurance and that just, I know for other people struggling with this, that is such a big consideration. So, we felt really happy that we could move forward and not have to think about the financial ramifications of it. (4.1, 259-262)
>
> Massachusetts State law requires insurance companies to cover all Assisted Reproductive Therapy. So, that was fantastic. I think that I did have a limit on the number of cycles that I was allowed to use. I think that there were six. So, I did have the sense of a looming number that I can have. (4.1, 266-269)

Research Question #1(a): Summary

Participants' experiences of inclusion during the temporal period surrounding their initial diagnoses encompassed the supportive roles of other individuals, including family, friends, partners, along with a few remarkable health professionals and work colleagues. In their contemporary, quotidian experiences of living with their conditions over time, participants also included the factors of self-advocacy and passing (e.g., non-disclosure), factors which particularly helped to facilitate inclusion within their work settings. The material factor of technology was also prominent in enhancing two participants' experiences of inclusion.

Research Question #1(b): Results

Research Question #1(b): What are the lived experiences of exclusion or marginalization for women with hidden disabilities?

Results comprise data from participants' narratives compiled from all three in-depth interviews, with primary data being drawn from the first and second interviews. Results are stratifed into two sub-sections: a) experiences of marginalization and exclusion during the initial period during which participants were undergoing and managing the initial diagnosis of their respective conditions; and b) experiences of marginalization and exclusion over the course of daily living after diagnosis.

Marginalization or Exclusion during the Diagnostic Period

All four participants expressed feelings of marginalization, shock, and aloneness during the time period in which they were first diagnosed with their respective conditions. These acute feelings of marginalization and exclusion were initially triggered by the medical system and health professionals within that system, which ironically was the very system generating the label of the diagnosis. Participants also expressed feelings of marginalization as a result of inadequacies within the medical system to provide integrative follow-up care after the initial diagnosis.

Marginalization by the Medical-Health Care System

In Sam's experience, the road to an accurate diagnosis of Addison's disease was arduous and non-linear. Physicians within the traditional medical establishment both questioned and dismissed the legitimacy of Sam's self-report of presenting symptoms. Physicians assumed that she was presenting with an eating disorder rather than with a potentially life-threatening condition due to adrenal insufficiency, arising from

insufficient hormones produced by the adrenal glands. Sam recounted the systemic challenges that characterized the period surrounding her diagnosis, including her feelings of frustration and aloneness:

> Addison's disease was a little more traumatic in terms of diagnosis. Over the course of six months, I was losing weight, starting to throw up after I was eating. I went to see general physicians. I actually had an endocrinologist at the time because of my hypothyroidism they were just making certain the dosing was right. Because Addison's disease is such a rare disease, it is about the last thing that anyone thinks of when you walk through the door, especially when you are a woman and it would make more sense that you are either pregnant or you're anorexic. So, I got lots of questions about that. Over the course of five or six months, I saw multiple general doctors. I saw endocrinologists. I was actually convinced to go see a psychologist who of course was convinced that I was anorexic and lying about it. By the time I got into the hospital, I had lost 20 lbs. (1.1, 17-25)
>
> So, it is hard when you are young and you have experts telling you one thing and nobody could help—I just felt like nobody could help me. That was the most frustrating thing. I felt like I went to all the places that I was supposed to go to and nobody could help me. (1.1, 122-125)
>
> I remember checking myself in on my birthday and being so happy to check myself into the hospital and think that someone is going to have to help me because I am in the hospital. (1.1, 168-170) Pre-hospital, I had very few advocates. (1.1, 182)
>
> I was single, professional and you know, when you have seen lots and lots of doctors and no one can find a physical problem and everyone is telling you that it is probably in your head. Yes, your boyfriend is advocating for you, but he doesn't know any more than they do. It is not that he doesn't believe you but he doesn't have another solution. Honestly, I was very alone. (1.1, 190-193)

Anna experienced the shock of her initial diagnosis of multiple sclerosis abruptly from a nurse. In her own words, Anna recounted this experience:

> They were doing all of these things and I didn't know what was going on and then this ridiculous nurse came in and said, "Okay, I have to get the Optho Neurologist because I think that you might have MS." I was like, "Shut up!" It was totally scary! (2.1, 30-32)
>
> I just thought it was very insensitive. (2.1, 34)

I only remember that one moment of insensitivity. (2.1, 49)

Anna also spoke to the feelings of shock, aloneness, and alienation immediately following her diagnosis. These feelings seem to have been compounded by a lack of appropriate, general psychosocial support recommended by her medical team:

I think that I just felt really all alone. (2.1, 171)

I didn't like the support groups. (2.1, 212)

…none of it sounded like my experience. It would be like going to buy a car and you know that you want a hybrid but then someone makes you look at all of these others cars, but that is not me. You know? So, I really didn't like the support groups. (2.1, 214-216)

The medical team recommended this *knowledge is power* and they have pamphlets about this and the support groups and then they had young people support groups, so not just the people that were really in a bad way. That was the sort of thing and like I said, I did not find it very helpful. Those were the recommendations that they had. (2.1, 223-226)

It was such a shock. All of the sudden your whole life switches from just normal and happy and yeah, I am just going about my thing, to the hugest chronic thing FOREVER. (2.1, 463-465)

Emily's experience of marginalization and exclusion by the medical establishment included being a participant in medical grand rounds, a medical school pedagogical teaching tool, following an initial misdiagnosis:

I was part of grand rounds! Which was an experience because we went into that day and I went with my mom, my mom was there—we didn't know a lot about me potentially losing my vision. We didn't have any background, and it was a very rare disorder that they were talking about and my mom said, "Well, if it is what it is then I am throwing your rear in the car and we are going to drive across country to see all of the beautiful sights" because we just didn't know how fast it was going to go. (3.1, 45-50)

So, we went through grand rounds, and I had an angiogram and by the end of the day we walked out and two days later we got a call saying that I was confirmed diagnosis for Stargardt's Dystrophy which is a juvenile genetic disorder—none of my family has it. We don't know really the history there because there is no history. Going back to the experience of grand rounds it was very intimidating

> because there was a couple of other families there with younger children and everyone was so somber and quiet and I get really hyper in hospitals—it is probably a defense mechanism—and it was just an odd experience, having the doctor come in and look at my eyes and then having seven or eight doctors, probably med students come in and look at my eyes. (3.1, 50-57)

Subsequently, the medical team then shared the news of Emily's definitive diagnosis of Stargardt's Dystrophy with her parents first, rather than including her in the conversation with her parents:

> So anyway, the doctor called and didn't talk to me, talked to my parents, which looking back; I probably should have been on the phone conversation for that. My mom hung up the phone and since she started crying and at that point I was just telling her it was going to be okay. I didn't really have a reaction at that point. It was more me comforting my mom because I was only 14 or 15 and I didn't understand what was going to happen. Anything that we had been told up until that point was like *don't worry it is a natural and slow progression and you won't lose all of your vision.* So, they were really sugar glazing it if you will. (3.1, 71-77)

In Lynn's case, the diagnostic process was protracted, with the diagnosis being continually revised even after treatment and intervention commenced. This meant that she had to constantly adapt to shifting parameters of an indeterminate diagnosis, namely unexplained infertility, with a non-definitive etiology that was subject to constant revision with each subsequent course of treatment:

> Because my disability is infertility it actually was a rather lengthy process to figure out what was happening. (4.1, 11-12)

> …we ended up meeting with a specialist in March of 2011. She rather abruptly told us that we were infertile. She just said it like that. She said the definition is that you had unprotected sex for x amount of time, which you have had and therefore you are infertile. (4.1, 26-29)

> …for us it was extremely emotional because we hadn't even really thought at that point that anything was wrong. It was really like we felt this label was given to us. We had to reconcile that with feeling like—we had suspicions that something was taking longer than it should or longer than normal, but we never really thought that that would be us. (4.1, 40-43)

> Especially because I felt that at 33 compared to all of my friends and family members that I was right around the right age and everyone was kind of in their early 30s and with a few exceptions even older than that when they were getting pregnant easily. So, it didn't even occur to me that it would have been an issue. (4.1, 44-47)

> …they only suspected male factor, but the main label we had was unexplained and unknown. (4.1, 114-115)

> …it was rough. By the time that we got to May, we were still diagnosing. (4.1, 156)

Marginalization by Others

In Anna's account, her initial adjustment to the diagnosis of multiple sclerosis was compounded by two additional factors: a) a difficult personal relationship and b) lack of support by some colleagues at work in a stressful work environment upon her return to work following her diagnosis. Anna found that her diagnosis exacerbated the equilibrium in her primary personal relationship:

> The hardest parts were this relationship. (2.1, 331)

> I think that the MS just threw into the mix all kinds of stuff so the stress like I mentioned of now it redefines the relationship. I am the person with the problems and she was the person who had to help me out and be supportive but still we would argue. (2.1, 335-337)

In addition, the degree of marginalization that Anna also experienced in her work environment, following her disclosure of her diagnosis, was a primary factor in her decision to decline a pivotal career opportunity to be Interim Executive Director at the same organization.

> I had to take time off of work and my work situation also wasn't the best. I remember them giving me a hard time. But, it was like, I can't see. I can't work! (2.1, 69-70)

> At that time, the Executive Director was leaving and the Board asked me to be the Executive Director (ED). I was just a kid and I was really good at my job and everybody loved me. It is not like I couldn't have made a good ED . . .

> (2.1, 311-313) They wanted me to be interim and how was that not just the best opportunity ever, but I just couldn't do it. I just had too much going on with the health stuff and I thought: I can't do that to myself. (2.1, 321-323)
>
> I think the job stuff was big when I didn't take that position and because of the way I had been treated when I had my first incident or episode, I remember because of the way that they treated me and then because of the kind of life that I wanted to lead and the lack of stress. It really seemed like the smartest work thing to do. It was the best thing to do! (2.1, 526-529)
>
> So, I mean to not take that, it was really because of this. Because of the way they treated me when it happened and all of that. (2.1, 541-542)

Marginalization Arising from Material Interactions

The material factor of gender played a significant role in the negative experiences that Sam and Lynn shared during the journey of arriving at a diagnosis of their respective conditions. In Sam's case, because she was a young woman presenting with initial symptoms of significant weight loss, nausea, and vomiting, the default assumption by medical professionals was that she had an eating disorder or was pregnant, rather than having a very rare chronic illness, such as Addison's disease.

> Also, during that time, I think maybe because other doctors thought he was diagnosing something that was not probable, they also assigned me a Psychologist who once again was insistent that I had anorexia and even though I would tell them that I didn't have anorexia, I remember him looking me into the face and saying, "You know, lying is actually a symptom so no matter what you say to me, I am not going to believe you." (1.1, 57-61)
>
> Let's just say when it came time to pay the hospital bill; I refused to pay the Psychologist. (1.1, 69-70)

Because of the medical establishment's continual dismissal of Sam's self-report of her worsening symptoms of nausea, vomiting, and weight loss, she herself began to harbor self-doubt about the etiology of her symptoms:

> You knew something was seriously wrong but when you go in and you see multiple doctors and they pretty much all tell you that it is all in your head, then you start thinking that maybe it is all in your head. (1.1, 114-116)

> They definitely thought that it was an eating disorder. I knew that it wasn't because I wasn't choosing to go into the bathroom and throw up right? I just had to throw up. (1.1, 121-122)

> **…**when you are really sick but it comes on gradually, you don't really realize how sick you are so it doesn't really occur to you to tell people along the way, especially when no one is really believing what you are saying anyway? (1.1, 197-199)

> The medical establishment surely was not believing me because they are trying to look for the most common denominator—young women usually come to us because they are pregnant or they are anorexic. They don't really think out of the box unless they have reason to. (1.1, 203-205)

> It was frustrating. It was debilitating. You start to feel self-doubt, right, like, what is going on in my head? Why is this happening when no one else seems to think there is a serious problem here? (1.1, 356-358)

Similarly, the role of gender also figured as a prominent factor in Lynn's sense of marginalization while undergoing the protracted process of gaining a determinate diagnosis. Lynn expressed that the dialogue and interaction with the medical establishment about the potential etiology of infertility was specifically directed toward her as a woman, rather than to her husband as a male partner or to both her and her husband as a couple:

> …this doctor in particular had a really hard time relating to us as a unit. She considered me as her patient and my husband was just the, some guy I dragged in with me. She wouldn't really look at him during the appointment. She was engaging with me and he was just kind of an accessory. So, it was very much directed at me, even though at that point they had no idea whether it was one of us or both of us or what. (4.1, 33-37)

> While I am processing my own diagnosis with this condition and feeling like a lightning bolt had struck me. I felt knocked over by it and totally unprepared to hear that. (4.1, 80-81)

Over the course of three cycles of treatment via assisted reproductive technology (e.g., in vitro fertilization or IVF), the inchoate, emerging diagnosis was unexplained fertility, with a suspicion of potential male factor fertility issues along with diminished

ovarian reserve. Lynn articulated how the latter component of the working diagnosis, pertaining to ovarian reserve, made it uncomfortably seem as if it was a "female issue" (2.1, 194):

> Going through these three cycles they told me—the suspicion was basically something must be wrong with you because these pregnancies aren't taking. They did a huge work up on me to figure out whether I had anything that would lead to reoccurring miscarriages and they uncovered nothing. Everything looked great. So then, at the end of all of that, the discussion was really more about how it must just be that the quality of embryos we were producing were poor and that was about me and not my husband. So, then again, we are kind of swinging backwards. We are swinging back to me, so now, not only do we have this unexplained label, but we also have suspicion of the male factor and we also have suspicion of diminished ovarian reserve. (4.1, 156-164)

> So, through it all, by the time that we got to May of 2012, we finally had this sense that it was on me. I really felt like it was something that my body was unable to do or wasn't doing well any longer. Whether it could have been age-related or something or it was programmed into my DNA, it was just that I was not creating quality eggs. (4.1, 173-177)

> At that point, I accepted that that was our final diagnosis, that there may have been something suspicious on the male side but that in general and through the three IVFs, he always did really well, so for me it really felt like a female issue and it is my issue and it is something that I am struggling with even though as a couple it was something that we were going through together. (4.1, 192-196)

The role of age played into Emily's sense of marginalization immediately following her initial diagnosis. Emily discussed the difficulties of adjusting to the new terrain of her initial diagnosis as an adolescent. In her words, "it was a very uncomfortable entrance into disability" (3.1, 310-311):

> I think, and this is a lot of credit to my parents especially my mom, I really didn't have a choice at that point. I had probably thrown my hands off the wheel and said, "I don't know what to do here!" (3.1, 296-298)

> We set up appointments with teachers and my mom worked with and did all the liaison with the State to get me an IEP, an individual education plan, and go through that whole process which is absolutely painstaking. To be honest, it is probably not the best way to enter disability. It is very depressing because you go there, and it is a state-run facility so the upkeep is not great. They are not great

> at getting back to you. It just takes so long to get any accommodations. You go to a vision specialist that is not really used to working with kids. They usually work with older people, so I am now grouped in a demographic which I don't identify with. So it was a very uncomfortable entrance into disability. (3.1, 304-311)

In addition to the challenge of moving to a new school during her junior year of high school, Emily had to learn how to navigate and adjust to uncertain terrain as her vision continued to deteriorate over time:

> I remember sitting in this room and I was pulled from class. We were going to have a discussion about my IEP, so I was there, my mom was there, whoever does IEP was there and they were asking me all of these questions like: *What do you think would be helpful for you?* I couldn't answer any of them because I didn't know. I had no idea. I knew that I couldn't see the classroom board. I was not comfortable using binoculars in the classroom. (3.1, 323-328)

> I think from junior year to senior year I just had to figure out what worked best for me. (3.1, 409)

The material factor of economics, including the necessity of working while ill, was also highlighted in Sam's account. Sam noted that the role and limitations of health insurance coverage played a role in the diagnostic process:

> Insurance was different then and it was very limited as far as what you could and couldn't do. (1.1, 273-274)

> It was fortunate that I had health insurance, absolutely it was. (1.1, 397)

> …when you are single and you need the income, you keep working. You still have to pay the bills. (1.1, 403-404)

Marginalization or Exclusion in Daily, Contemporary Experience

Marginalization or exclusion in participants' daily, contemporary experiences of living with their respective conditions was attributable to a range of sources. These sources included friends or colleagues in social or work settings, as well as the medical and health care system itself. In some instances, marginalization or exclusion had roots in socio-cultural expectations of normative behavior. For each participant, a common

cause of experienced marginalization post-diagnosis was the very invisibility of the condition or disability. Specific examples from the accounts of each participant ensue.

Marginalization by the Medical-Health Care System

Sam shared the unexpected logistical challenges that she has faced in the ongoing management of her Addison's disease, a rare and chronic illness, after moving to the West Coast of the United States from the Midwest. One challenge was the dearth of local medical professionals who have both knowledge and clinical expertise in treating Addison's disease. The second obstacle for Sam was the surprising difficulty of locally obtaining all of her necessary medications after relocating from the Midwest to the West Coast of the U.S. Sam still has to order her necessary medications from Minnesota, the state from which she had re-located:

> Another challenge and it is not a day-to-day challenge, but getting back a little bit to regular medications that I take, I think I spoke last time about my need to have a vial of Dexamethasone and syringes on hand at home and at work. Now that I live in California and the population doesn't predominantly have North European heritage and Addison's disease isn't common out here, I actually cannot find that medication out here. I have to call into a Minneapolis clinic and get it shipped to me. Once again, not a huge hassle now that I have figured out the system, but when I first moved out here it took me a long time and I had to go to many pharmacies to get the actual medication that I needed. I was the one who had to finally suggest to my endocrinologist that she should call the prescription into Minneapolis because that was just the easiest route to get it. (1.2, 28-36)

> I would call it more of an inconvenience and just primarily brought on, in terms of major inconveniences, moving to California and not being able to find a doctor. Even the doctor that I currently have, as far as I can tell has never treated a patient with Addison's disease. (1.2, 88-91)

As a result of the scarcity of medical professionals who have experience in treating Addison's disease in her local area of California, Sam has had to re-engage her endocrinologist in the Midwest in her health management:

> It was very evident to me that I was going to have to manage what was going on and have someone on hand in case I ended up in trouble. But, I feel a lot happier now that I have reconnected with my Endocrinologist in Minnesota. (1.2, 160-162)

> It had never occurred to me that this area and the resources within it including a University and all of the other hospitals here wouldn't have the most advanced medical treatment and so it was very surprising for me to get here and not being able to find someone who knew much of anything about Addison's disease. I asked all five or six Endocrinologists that I went to whether they had patients and I think a couple had one or two, but there were plenty who did not have any. (1.2, 191-196)

In addition to these two significant logistical challenges, Sam also noted lacunae in both clinical and research resources for patients with Addison's disease:

> It would be awesome if they had a directory of what everyone's specialties were, but when I do research online and go look at a doctors profiles and what they specialize in, I can't even find any reference to Addison's disease, so for them to take the time to spell out specialties in some directory for them to use, I can't imagine who would organize that. (1.2, 211-215)

> I guess it is also a little bit frustrating because finding new information, any up-to-date research that is really relevant to your day-to-day life is really difficult to find. (1.2, 246-248)

> There is research, and I am actually lucky that being an employee of a university, I can actually get to that research relatively easy, probably more easy than other people. But, there is just not a lot out there. So there is not a lot of learning that I have done in the years that I have had it and once again, who is really going to put research dollars into something that doesn't affect that many people? It just doesn't economically make sense. (1.2, 248-252)

Following the protracted, arduous time of obtaining a clinical, working diagnosis for her condition, Lynn observed that her medical records now convey a label that can be further marginalizing:

> I feel like every medical record that I have now has infertility stamped on it. (4.3, 386-387)

> Infertility. Unexplained. Isn't that interesting that we walk around with these documents that categorize us into these different disease classes. (4.3, 395-396)

> Infertility. Unexplained. That is not going to be taken off. That is there forever so I think a lot of it is about the medical system giving this label and there is the interaction that my world has with that label that perpetuates it. People who know me and know this story, I think, will forever think of this as part of who I am. It doesn't just get taken away, so I think it is both. So it is permanent. (4.3, 413-417)

Marginalization Arising from Invisibility

All participants articulated varying degrees of marginalization that arose from the invisibility of their respective conditions. Feelings of marginalization and exclusion existed even with participants' access to appropriate institutions and clinical service providers. Sam shared her experience of discovering others' lack of understanding and awareness about a rare, chronic illness:

> …no one had ever heard of it before so it doesn't stick (1.1, 457)

> It is that someone has a disease that you have never heard of before and you can't go look up without going to a library, so it doesn't stick. It is not like now where I would hear that my colleague has lupus and I might go and Google that. So, it is just such a different time (1.1, 470-473)

> Again, no one knows what it is and they don't have time to create perceptions and that is frankly why I don't bring it up. What is their response going to be unless it is somehow relevant to the conversation and sometimes it is, but not very often. (1.1, 705-707)

Sam wore a medical alert bracelet and expressed surprise that others rarely noticed it. When the bracelet was noticed by others, it triggered a question in Sam's mind regarding how much information may or may not be appropriate to share depending on the audience:

> The bracelet only indicates Addison's disease (and an allergy to penicillin). (1.2, 62)

> It is surprising how many people don't notice it to be honest. (1.2, 70)

> When they do notice it, it is always a question in my mind: how much information do they really want? Most people think it is for an allergy or something that is

> really easy to explain and so depending on who it is, I have to think about whether or not they really want a lot of information about what is going on. (1.2, 70-73)

Anna shared the primary conundrum in her daily experience as being one of keeping her condition undisclosed to others outside of her immediate family and select friends:

> In thinking about it, I think there are two parts. One is this not telling people part of it that comes up a lot in the daily and then the other is the actual, just having the invisible disability just happening. So, like, not feeling well and people can't notice, even people who you know and who know about your disability. (2.2, 9-12)
>
> The biggest thing in my daily life is the hiding out part of it. (2.2, 14)
>
> I don't like having to lie, but I don't want to tell the truth. (2.2, 24)
> On the other half of the—if I am not feeling well, with people who do know—R. always can tell. So, I can't really hide that. (2.2, 54-55)

Anna chose not to disclose information about her disability in her current professional setting as a result of an initial, negative experience of full disclosure at work following her diagnosis of multiple sclerosis:

> Yeah, it is pretty much just everybody except work people, which is a big part of the time. I did have to tell my old boss when I first started. (2.2, 512-513)
>
> … it [disclosing] really changed the dynamics and it changed how, I feel, like my work was seen and how we interacted together. I think she was upset that I hadn't told her because we got along really well before, but things just kind of deteriorated. (2.2, 548-551)

Emily expanded upon a number of insights about the challenges she was facing at her current workplace. These challenges seemed to arise as a consequence of the very invisibility of her disability, as well as a lack of general interest from many of her colleagues in learning more about her disability or about the accommodations she may need:

> On a daily basis, I don't think the average person sees someone, like a twenty-something-year-old, because blindness also happens when you are older right? So, it is associated with aging. (3.2, 131-133)
>
> That is something that I get all the time even now: *You don't look blind or you hide it so well.* (3.2, 143)
>
> I think that is just the nature of the beast in being in a new environment and being with a new group of people. Even though I announced on day when I was going through my introductions I said, "Also, just to let you know, I am visually impaired to the extent of being legally blind. I have central vision loss. I will let you know if I need anything but it is just something to be aware of and I invite questions." I just haven't gotten that interest or exploratory questions back at me from my colleagues. (3.2, 267-272)

Although her workplace provided Emily with excellent hardware accommodations, such as a closed circuit television (CCTV), she has found that she has to be "constantly aware and advocating" (3.2, 227) for herself in her professional setting. By providing a few examples, Emily shared some of the difficulty in social contexts that she was experiencing as a consequence of being unable to easily read non-verbal cues and facial expressions due to the deterioration and loss in her central vision. An added challenge was her colleagues' forgetfulness in remembering that she indeed has central vision loss:

> I can't see their face to read their visual expression, and I can't necessarily read handwritten things. I would equate my media experience now to being like a teleconference. It is not FaceTime, so I just can't take any kind of visual cues out of it. So I can't necessarily judge in a room any nonverbal cues. That is something that I am currently challenged with but not necessarily that everyone at that table is aware of because I think that they just forget. (3.2, 262-267)
>
> What I am struggling with is how to deal with the social interactions that I am losing out upon. (3.2, 324-325)
>
> So, if I am networking at a conference for example, I cannot see name tags. So, I can't pick and choose who I go up to and talk with or if I talk with someone, I cannot use their name in my conversation. Or if I am in a large group of people, I may not be able to see who is looking at me to have that connection and then go

> over and talk to somebody. It is just little things like that, that I have not found workarounds for. (3.2, 325-329)
>
> …the big thing that I am struggling with is social interactions and how to deal with that in a professional world but also in a personal world as well. (3.2, 380-381)

Emily remained hopefully optimistic that others would have increased awareness about the needs of persons with disabilities in the future, but acknowledges that the process of constantly educating others can be fatiguing:

> As much as it is frustrating, I still think to myself, *They will be more aware next time.* I am not unfamiliar with blazing the trail in terms of creating awareness among coworkers and friends about disability. That is the thing with invisible disabilities. People come into contact with disabilities all the time; they just never really know about it or they don't think about it in that way because they don't fit the disability mold in their mind—their picture of disability. As tiring as it can be, I take comfort in that fact. (3.2, 290-295)

Lynn shared that a sense of marginalization arose from a combination of factors. Two key factors were the invisibility of her condition, compounded by the general lack of public understanding about infertility once she disclosed facts about her diagnosis.

> I think that everybody really didn't understand what that label meant. They heard infertile and they thought *barren* or whatever the old word was, like completely incapable ever! (4.1, 70-72)
>
> It was totally invisible to others. The only people who knew were people that I told and at that point, even talking about what we were doing was hard and then adding on the miscarriage part was even more difficult, (4.1, 435-437)
>
> Because a lot of people get scared or uncomfortable or anxious because they think that they are going to say the wrong thing and so they don't say anything and that just makes me feel more awkward. (4.1, 613-615)
>
> In some cases, it got to the point where I felt like this isn't invisible. It is the 6000 lb elephant in the room because everybody—people now know and they don't know how to address it and they don't know what the right thing is. So, they get uncomfortable and in some cases, they didn't want to engage with us because, I guess, it was too hard. (4.1, 615-618)

Lynn also elaborated upon the early challenge of information management surrounding her diagnosis:

> …in contrast, I will talk a little bit about what it used to feel like because in the beginning phases, it felt like a weight that I was carrying around and something that was a burden. When I think about spending time with friends or other people, I used to wonder if it was going to come up and if I would have to talk about it. It would be very stressful. (4.2, 10-14)

> When I think about when we first moved here three years ago and were meeting new people and I would just think about if the questions would come up—you know the dreaded question of: Do you have kids? (4.2, 22-24)

> That was what was so hard about it was that because it was such a benign question to them, it would almost feel more hurtful sometimes because it would be something so flippant that people would just throw it out there and not be thoughtful about it. (4.2, 39-42)

> I expected people to get that it wasn't something that was easy, and it wasn't a benign topic. But of course how could I ever expect anyone to be able to know what was going on? So, it was a very stressful time because I would anticipate with each new friend or each new person we met having that conversation with them and that was very emotionally exhausting, and now it is something in contrast. (4.2, 42-46)

Marginalization Arising from Material Interactions

The material combination of gender and sociocultural norms, relative to gendered expectations for women, also figured as a leitmotif in Lynn's recounting of aggregate, daily experiences of marginalization:

> …there is this expectation of doing the next step. You partner up and then you have babies. That is what people do. (4.2, 32-33)

> I felt very strongly that this whole process was very much directed as me as the woman. (4.2, 83-84)

> I just think, again, it highlights how much more of a sense of the burden is on the woman. For a guy, it is a very different experience. (4.2, 105-106)

> It was time to pull back and I think part of the reason that I hadn't done that up until that point was because that I was again, this comparison to other people

> because at that time there was a constant barrage of babies and pregnant bellies and I was literally feeling like I was getting left behind... (4.2, 573-576)

> There are these cultural norms and if you do not meet these milestones at these given moments then you are automatically shifted outside of that—what everybody is experiencing thing. (4.3, 586-588)

Lynn acknowledged a disconcerting sense that she was somehow not fulfilling sociocultural expectations of a female partner when she and her husband were considering alternatives to having children of their own biological make-up:

> …it was like I got to the place of being perfectly happy with adoption and it is going to be amazing, and I always felt a sense of real loss for him in not being able to do that for him. It was really difficult. It is the only part of it that I never really felt resolved because it would be him letting go of something that I don't think he was ready to let go of. So, again, it goes back to feeling like I am failing in my job as his female partner to provide a baby of his genetic make-up and my genetic make-up and that felt difficult. (4.2, 152-158)

In addition, Lynn experienced an additional layer of marginalization connected to the materiality of assisted reproductive technology, the very technology that simultaneously increased the range of alternatives for creating a family even as it delimited what biological materials she and her husband could use:

> I think that the interesting part of the tension that came up around that conversation was around my preference would have been adoption and his was to try donor eggs at that point. The sperm was not like we needed donor sperm; it was donor egg. That was hard. (4.2, 200-203)

For Emily, the material factor of economics, specifically the need to find a job and launch her career, played into an acute sense of marginalization and exclusion in her first year upon graduation from college. Emily described the year following her graduation from college as a "year of challenge" (3.1, 603) and a year of "just feeling lost" (3.1, 646):

> After college. So, I had a year of unemployment and was boo hooing that I was blind and coming to terms with the fact that I was blind. (3.1, 598-599)

That was a year of challenge. (3.1, 603)

During that year, Emily faced both logistical and personal challenges in coming to terms with her disability and moving forward into the future with independence as a young adult:

> I wasn't doing anything. I was living at home and where my family's house is, there is no public transit, so I was having to depend on my mom for transport everywhere which was killer for my independence. (3.1, 637-639)
> A lot of fear—a paralyzing fear really because I didn't know what I wanted to do and the world was too big that I couldn't feel like it could be my oyster. (3.1, 643-644)

> A lot of anger came out and it was very, very, very misdirected at my parents. Yeah, probably a lot of anger and fear (3.1, 644-645)

> So, yes, that year I did a lot of soul-searching and probably accepted my own disability (3.1, 683)

Research Question #1(b): Summary

Participants' accounts of marginalization or exclusion during the diagnostic period of their respective conditions all included the medical establishment as the primary structural factor contributing to their feelings of aloneness and shock. The material factors of gender, age, and economics also were contributory elements to participants' sense of dis-enfranchisement. In their daily experiences of living, all participants spoke to the invisibility of their respective conditions as being a key factor undergirding their initial sense of marginalization. A few participants again named the medical establishment's role in unwittingly functioning as an agent for exclusion, rather than inclusion. Finally, for a few participants, material interactions, which contributed to sense of marginalization in their contemporary experiences, comprised a combination of gender and sociocultural norms, relative to gendered expectations for women, along with economic factors.

Research Question #1(c): Results

Research Question #1(c): What are the corporeal dimensions (e.g., issues of embodiment) of lived experiences for women with hidden disabilities?

As in the previous two sections, results comprise data from participants' narratives culled from all three in-depth interviews, with primary data being drawn from the first and second interviews. Results are divided into two sub-sections: (a) participants' descriptions of issues of embodiment during their initial diagnostic periods; and (b) corporeal dimensions of participants' experiences over the course of daily, contemporary living.

Issues of Embodiment during the Diagnostic Period

Sam shared her presenting symptoms prior to her protracted diagnosis of Addison's disease, which included significant, unexplained weight loss:

> Over the course of six months, I was losing weight, starting to throw up after I was eating. (1.1, 17-18)
>
> By the time I got into the hospital, I had lost 20 lbs. (1.1, 25)
>
> You feel terrible. You know that you shouldn't be throwing up all the time. You are losing weight. (1.1, 109-110)
>
> I had to force myself to eat. (1.1, 498)
>
> Because if I hadn't had that and hadn't forced myself to eat something, I might not be sitting here. So kudos to the stoic mid-western upbringing, three meals a day, it is just what you do. It is a pattern. (1.1, 502-504)

Sam also expanded upon the sheer physical challenge of working during that time period when she was ill and struggling to obtain an accurate medical diagnosis:

> I was working during that time period and it was really hard. It was really hard to get up in the morning because when you don't have any adrenalin, it is really hard to get up in the morning. When you are sick as can be, it is really hard to get up in

> the morning. When you can't keep food down, it is really hard to get up in the morning. (1.1, 92-95)
>
> It was a huge challenge to get out of bed. (1.1, 210)
>
> It was a huge challenge to eat something and wonder if I was going to throw it up. It was a huge challenge to get into work, to work a full day, come home and go through the dinner cycle again of, okay, let's see if I can keep this down. (1.1, 214-216)
>
> It was a challenge and I was just happy to make it through the day. (1.1, 223)
>
> And, it helps that I was young, right? I was young. I was mid-western. I was stoic right? I mean, it helps to be young and tough and I had doctors tell me that, you know, had you been older—you shouldn't have made it through right? (1.1, 227-229)

After finally obtaining an accurate diagnosis of Addison's disease, Sam recalled the immediate difference in physical embodiment she experienced after receiving her first steroid treatment:

> I was saying, "Thank God!" Thank God to have a diagnosis, and I remember vividly the first dosage of the prednisone, the steroid that they use to replace adrenalin, that they gave to me… (1.1, 241-242)
>
> But, I remember it was like a curtain had opened, and I could think again. I can actually think! I remember lying in the hospital bed at 2 am and thinking this is heaven, I can actually think. So, I was thrilled. (1.1, 243-245)

Anna described the initial symptom of optic neuritis, which ultimately led to her diagnosis of multiple sclerosis (MS):

> I didn't think it was young, but now, 24 sounds so young. I got this absolutely classic MS diagnosis. I got this optic neuritis. (2.1, 16-17)
>
> I thought I had a scratch on my right eye and so it got worse throughout the day. (2.1, 23-24)
>
> This Optho Neurologist was there looking and my eye and it just got worse and worse and worse this whole time. So, by the time I got out, it was pitch black. (2.1, 41-42)

> it just kept on getting blurrier and blurrier, so the optic neuritis is where your optic nerve is cut or attacked, and your body goes to help repair it but then it sort of swells around the area, so that is what causes the symptoms. So it got worse and worse and worse and throughout the evening, I just will never forget. (2.1, 44-47)

> Then, it was like, "Wow. Oh shit! I really can't see!" (2.1, 53)

> Then, six months later, during the summertime, I had my second episode and then I got diagnosed. (2.1, 94-95)

> So, all my vision came back—I forget to say that sometimes. The prednisone steroid—so all of that swelling happens and then it takes down the swelling and then the optic nerve can repair itself. (2.1, 97-99)

> But particularly the optic neuritis stays very vivid in my mind. That is a big one. (2.1, 148)

Anna used a visual metaphor of endogenous, alien material internally attacking her to describe the phenomena occurring within her body with the MS. She described it as "this big nasty thing happening to me inside" (2.1, 520) and further elaborated thus:

> I felt so gross. I felt like I had this stuff in my body, and it just felt really weird and sort of gross and foreign. It was like: Why is my body doing this to me? I was having to take the shots and there would be a little mark after, a little red spot, and seeing that MRI—the picture of all of the different lesions on there—it was just like, I couldn't believe this is all in my head going on. It just felt really gross. I suppose that I had my own self-esteem issues where I needed a little more compassion. (2.1, 341-346)

> It would be this nasty black goo inside of your body doing stuff to you that isn't natural. It is just not right. You would think after how many years of evolution that our bodies would work better. I would think. (2.1, 662-664)

Emily recalled the initial changes in her central vision as an adolescent, changes which catalyzed the course of events leading to her diagnosis of Stargardt's Dystrophy. She first noticed the subtle, but significant, deterioration in her vision while playing softball:

> So, in 1999, I was about 14 years old and I started to notice some disturbances in my vision. At that point, I had glasses since the first grade and I knew that my

> vision was pretty horrible without being corrected, but my doctors had always been able to correct me back down to 20/20/20/30, you know, pretty close to the average Joe. (3.1, 15-18)
>
> The first time that I remember that there was something wrong with my vision, I was playing softball, and I was in right field, of course, because I was a crap player. I remember that the ball was coming towards me and it was flying through the air against the blue sky and looked at it and it made a skipping motion. As I came to find out, I was losing my central vision, so whatever I looked directly at, there was a big gray blur in front of it, so every time that I looked at it, it would disappear and since it was a moving object it would just continue to go over my head. That was the first time I remember thinking that something was not right. (3.1, 20-26)
>
> …from December to September of the following year, my visual acuity had decreased from 20/40 to 220/100, so it was a pretty significant jump. (3.1, 90-91)

In contrast, Lynn did not experience any overt symptoms that led to the unexpected diagnosis of unexplained fertility. Even with initial intervention, Lynn experienced minimal side effects and sequelae:

> For me the treatment, and this is interesting because maybe it does speak to what the actual physiological processes were that was happening, but I actually didn't feel super affected in any way by any of the treatments with exception of the fact that when you get somewhat far along in the process you are just uncomfortable because you are kind of bloated and sore. But aside from that, I never experienced anything that would require me to take a day off or anything like that. It was manageable for me. (4.1, 237-242)

Issues of Embodiment during Daily, Contemporary Experience

For Sam, the corporeal dimensions of managing Addison's disease have been straightforward through intake of daily medications. Complications can arise, however, in cases of stress, injury or trauma. Consequently, Sam has to be cognizant of managing potential issues arising from stress, including stress from exercise:

> Luckily the day-to-day experience is really pretty simple. I take drugs twice a day—in the morning and in the evening—so they are little bitty pills, easy to take, not any complicated process. (1.2, 11-13)

> When things get complicated is if I end up in the hospital or sustain some type of injury because if you get into a car accident the first thing that happens is your body starts kicking out a bunch of adrenalin to prevent you from going into shock and since my body can't do that, any type of accident like that would be very traumatic. (1.2, 13-16)

> …one of the challenges with Addison's disease is that your body just is not set up to handle really any kind of stress because adrenalin is what helps normal people manage stress in addition to having energy. I know that there are some Addison's patients who don't even exercise or can't have stress at work; anything that produces every definition of stress is a challenge. Luckily, I don't seem to have some of those challenges that other people do with stress or exercise stress, but I have to be aware of them. (1.2, 339-345)

> Luckily, contemporary [living] is relatively easy if things go as they should. (1.2, 354)

Anna spoke of the primacy of making self-care and feeling well her key priorities in daily embodiment and management of potential symptoms of MS. With these as governing priorities, Anna has now been symptom-free for six years:

> So that is part of the everyday thing. It is that everything that I do relates to not having symptoms or not having an episode—eating well, sleeping on time, not stressing out—theoretically if I were exercising or meditating, those kinds of things would fit in. All of the things that I do are so that nothing goes wrong. (2.2, 103-106)

> I feel it is very manageable and that is part of what is complicated for me to separate between how have I grown in dealing with it and have I just gotten better? Or has my health gotten better? Because I have been really well for at least 6 years I haven't had any episodes or anything. (2.2, 117-119)

> Yeah. I can feel it inside. But I look just as though nothing was happening. (2.2, 138)

> I don't know how it is or what all has come together to make me feel so much better. But, I really think that not having the stress, any real stress of life, now everything that I do is just so that I can be happy and healthy. That is all I need to worry about. I don't need to think about anything else. (2.2, 304-307)

In previous years, Anna wrestled with the dilemma arising from the invisibility of her condition and the pain or numbness she may have been enduring while experiencing symptoms, symptoms that were imperceptible to others. Such numbness would occur in her hands, feet, legs, and face or lips in situations of heat. Anna recounted one recollection of this dilemma prior to her wedding when interacting with her fiancé and his family:

> So, some of the times when I had to deal with having these physical things inside when I didn't want to tell people because it wasn't on the outside, so they were *invisible, w*ith him and his family, so all of his family knew because we went for our wedding and they had to know because if I get hot my symptoms boil up. (2.2, 171-174)

> But I just remember having all of that pain and not wanting—it must have been at the wedding or something really early on because I really didn't want people to think that I was a loser and couldn't take this car ride. I kind of didn't want to miss out on it either. (2.2, 196-198)

In describing the phenomenon of experiencing these invisible symptoms, Anna noted the following:

> It is invisible. It is so weird and everything is going on as though nothing were wrong with anyone and I am trying to deal with all of this and I am miserable. I feel like it keeps getting worse and worse. I wanted to cry. (2.2, 390-392)

> Yeah, it is painful and just uncomfortable and it is just kind of scary even though I know that it is going to be okay. It is just really scary. (2.2, 400-401)

> I would say, it is a little sad when I have them. It is very conscious and subconscious. (2.2, 769)

Unlike Anna, Emily did not experience pain. However, she does experience vision fatigue. In addition, Emily also has the daunting challenge of needing to constantly adapt to the progressive deterioration of her vision over time. In light of this,

Emily experiences exhaustion from the ongoing need to problem-solve and create workarounds:

> Sometimes my eyes get tired from straining, so my eyes will get sore, but not pain (3.1, 860-861)
>
> I feel like my impressions and what I live with and how I live with it on a daily basis now is probably different [than] how I lived with it on a daily basis in college or 6 or years ago – or probably even 5 years ago. (3.2, 12-14)
>
> That is the thing with Stargardt's is that you just don't know how fast it is going to go. (3.2, 101-102)
>
> Eventually, it will deteriorate to the point where I probably do need a white cane to travel independently, and I look forward to that someday because, at the same time, it is a conflicting thing. I don't necessarily want people to instantly judge me for that, but there is also a relief in having people know up front, so I don't have to do that dance about when to tell them or how to make them feel more comfortable once I tell them, or just for people to remember because people forget a lot. (3.2, 102-107)
>
> …I think some of the hardships or exhaustion comes from that idea of trying to constantly problem solve or constantly have to do six or seven steps to do something that a normal person can do in one step. (3.2, 352-354)
>
> I think that it's just a process because it's something I deal with over time that gets worse over time. (3.2, 611-612)
>
> I definitely have thoughts where I'm like, "Okay, we can stop now. Like I'm fine just being this legally blind for the rest of my life." So, that I don't have to keep problem solving or keep figuring out new ways to do things and keep adjusting. (3.2, 616-618)

Lynn discovered that consecutive treatment cycles through assisted reproductive technology, whose outcomes included two early miscarriages (i.e., chemical pregnancies), began to take a substantial toll on her physically and emotionally:

> …after that second round which was emotionally exhausting because I think I was finally getting to the point where I was going to accept this, but also having that second early miscarriage really, really wiped me out and I physically felt exhausted. (4.1, 398-401)

After the second treatment cycle of in vitro fertilization (IVF), Lynn started to see an acupuncturist weekly, and these treatments helped to restore her to a sense of wholeness:

> I just felt like I was brought back from the dead in many ways. I just felt so much more within my body. (4.1, 426-427)

> So, aside from exhaustion and whatever two miscarriages will do to you physically, I was walking around like I was a zombie. So, she brought me back to myself and it was amazing. It just helped so much and also having the time that was cut out for me to go and do this thing. It felt really amazing and it felt like it was helping and it just made a big difference for me. (4.1, 427-430)

Like Anna, Lynn recognized the need to make self-care a priority during the course of conventional infertility treatment:

> I knew that physically, I had to address my health and part of that was coming to grips with stuff emotionally and psychologically. If you had seen me at that time, I think that I looked like a different person. Everything about me was so weighted down. (4.2, 493-496)

Material Interactions Impacting Embodiment

Material factors of gender and technology as social constructions surfaced in two participants' narratives. Anna reflected upon some of the material consequences that have resulted from her decision to focus on symptom-free embodiment. These included the decision not to have children, as well as volitionally resisting many of the socio-cultural norms expected of women:

> My sort of bottom line is more that I want my body to feel good. (2.3, 122)

> So, that means less stress, no children, which I had never really put in that whole context until now. I never wanted kids, but I think it is a big part of why I chose not to have them. It is because I don't want to add that to my life and if I wanted to and I wanted to deal with it and I wanted to feel crummy because of it, then maybe that would be okay. But my equilibrium or my priority is more on feeling good in my body and not on those kinds of things. (2.3, 122-127)

> So, getting away from—especially as a woman—all of these *shoulds* that I think I should do. Even if nobody cares, it is there. It is so hardwired. (2.3, 135-136)

Lynn addressed the material factor of technological intervention, via assisted reproductive technology (ART), and its impact upon her sense of embodiment. In particular, she expressed her reservations about the level and extent of externality involved with particular aspects of ART. The decision to move forward with in vitro fertilization was symbolic for Lynn in terms of the level of external intervention, outside of her body, that this treatment involved:

> For me, it was symbolic and it was a big step because it felt like a lot of intervention. (4.1, 336)

> We put the sperm in for you, but it was still kind of happening in my body but for me the taking it out of my body part was really a difficult piece of the story… (4.1, 341-342)

> Like taking out the eggs and fertilizing them with the sperm outside of the body and then putting them back in felt very—it just felt like a lot of intervention and I didn't know that I wanted that. So, it became for us, the real sticking point about whether or not we were going to go forward. (4.1, 346-349)

Even as a scientist, Lynn herself began to recognize her own limits with regards to the possible scope of technology's role in creating a family when a physician raised the topic of the potential use of donor eggs with her and her husband:

> I felt like why would we keep doing all of this medical intervention when we don't really have to? It was just that the physical parts of it for me were so hard. (4.2, 286-288)

> And this time it would be even worse because it would not even be my egg. It would be totally foreign. (4.2, 293-294)

> Even as a scientist, for me, it just felt like too much. I knew that that was approaching my limit, and I wasn't comfortable with that level of intervention because again, for me the goal was not pregnancy, the goal was a baby, a child. So, it didn't make sense to me why he thought that was such a great option when I felt like adoption solved the problem in even better ways. It is neutral and

> nothing has to be done to my body. Nothing has to be manipulated and it is something that we could work on together. (4.2, 299-304)

Research Question #1(c): Summary

In summary, participants described the physical experiences occurring within their bodies during the time in which they were undergoing their initial diagnoses for their respective conditions. In their daily lives after diagnosis, participants shared actions and strategies surrounding the physical management of their conditions. These actions have helped to obviate negative symptoms, often invisible to others, or sequelae both in the present and also in the future. The material interaction of embodiment, combined with gender and with technology as social constructions, appeared as leitmotifs in narratives of two of the participants.

Research Question #2: Results

Research Question #2: How do women with non-visible, hidden disabilities articulate the meaning of living with an invisible disability?

Results are drawn from participants' narratives collected from all three in-depth interviews, with primary data being drawn from the third and final interview. Results are grouped into the following broad themes: (a) reflections on philosophy of living; (b) turning points; (c) transformation; (d) redefining disability; and e) hopes and aspirations for the future.

Reflections on Philosophy of Living

Participants eloquently shared their philosophy of living, a philosophy now infused with their lived experiences of living with chronic illness and/or disability. Some

of these reflections framed participants' metaphors for life itself, as well as reflections upon how their diagnoses impacted their sense of identity.

Sam articulated a pragmatic view regarding what it means to live with a chronic illness, drawing upon the metaphor of life as a game of cards while also keeping a perspective on her condition in light of broader issues of health:

> I feel like everyone draws good cards and bad cards and this certainly falls into a bad category for me, but it is not nearly as bad as some of the other cards that people draw. So, I certainly try and keep a positive attitude and keep it in perspective how much worse my situation could be. If you go to the National Institutes of Health web site, you will see that there are an overwhelming number of rare diseases. I feel like I cannot feel too sorry for myself. (1.3, 9-13)
>
> So, overall, I am very aware that things could be a lot worse. (1.3, 17)

Anna reflected upon the dialectical conundrum that her health is always on her mind, and yet her condition of multiple sclerosis (MS) does not completely define her life:

> How can this be on my mind all the time? It is always there, but yet it has nothing to do with me. So, how do I—I am always thinking—say I have a symptom, do I say it? Do I not say it? I am always thinking about health, which I always do. Maybe all people do. I don't know. At the same time, it is like it has nothing to do with me because I am just living my life. I am just doing my things. I am going to work or cooking dinner or reading a book, so I don't know how those two things happen at the same time. (2.2, 78-83)
>
> But then, as a disability—it still sort of doesn't make sense like how that happens and how that affects who I am. (2.3, 31-32)
>
> Even…from the beginning, how can this be this thing that is so important—this thing and I am regressing back to my childhood with the "this thing" [the MS]? How can it be so absolutely relevant to everyday life and yet kind of inconsequential to identity? (2.3, 32-34)

Along similar lines, Anna also questioned what the parameters of disability are, posing these thoughtful questions:

> Should a disability impede you from doing certain things that you would like to do? (2.3, 86)

> And if doesn't, then is it one? Because I was reasoning: A disability is when there are things that you want to do or a life that you want to live and you can't because of some problem. But, I don't really feel that because I pretty much just live my life like I want. (2.3, 90-92)

Emily provided a positive perspective on the challenge of dynamically adapting to the progressive deterioration of her vision. This perspective was informed by her own history of living with and managing her diagnosis for more than a decade, as well as her own personal philosophy of life:

> For me, I have been living with this now for 13 years, so I don't really think about it that often because I have had so long to adapt and gain that confidence that I will adapt. And yes, it will get worse over time, but I will figure it out. That I have that reassurance and that sense of inherent self-worth that extends beyond having a disability, so through a variety of experiences, I have just come to terms with it, in the sense that I am a strong believer that things happen for a reason and those things that happen to you in life that are not your choice, whether you didn't get into that college, or you end up having a disability, that they happen for a reason and they help set you on a course where you are meant to be. (3.3, 21-28)

> I think definitely that courage is a big part of it. (3.3, 322)

> Yeah and it is stamina. It takes stamina. (3.3, 332)

In light of some extreme exigencies and tragedies in life, Emily acknowledged the following:

> Sometimes there just is no sense. There just isn't. (3.3, 356)

Emily also shared the following insight regarding agency, which also connects to her early decision to become her own self-advocate across different contexts:

> It really is a choice. I had someone say—not to me, but I was attending a conference around blindness—Blindness can either make you bitter or better. It is up to you what you choose. It is a choice. The challenges that come and meet you and especially the ones that force you to do things differently. It's a choice how they affect you and how you meet them. So, to have the courage to be able to meet them and let them better you as opposed to let them turn you, takes courage

> and it takes support from others and it takes—not the courage to overcome them, but the courage to ask for help. (3.3, 363-369)

Similar to Sam, Lynn also drew upon the metaphor of life as a game of cards in her reflections upon an unexpected diagnosis:

> Yeah, I would never wish it on anyone, but some of us get dealt this card and we need to learn how to get through it and to live with it. (4.1, 916-917)

For Lynn, coming to terms with her diagnosis was a cyclical process of learning to release control and then, through that release, ultimately regaining a renewed sense of control. Lynn spoke to the erstwhile feeling of her condition being an onerous weight that exercised control and caused pain:

> Now, it is something that I can bring up. It is something that I feel like I can address it. I can raise the topic and I don't do it in the way that is asking people when they are going to have kids. It is talking about what we've been through and our experiences, and I think in that way it is sort of taken it away from this idea of being something that I am dragging around and causing me pain and it was kind of controlling. (4.2, 46-51)

> It was controlling me and now I feel like I can control, at least, all of it is so uncertain that I cannot control what happens at all and I think that I have accepted that, but I can control how I talk about it and how I respond to what people ask me about it. It just feels like a lot of this process for me has been about that idea of control because it is such an uncertainty and you never really know what is going to happen and you never really know what is wrong or why. A lot of it for me has been finding ways to reclaim a sense of control over what is happening to me. I think it is very unsettling to live in place where you don't feel like you have control over any of it. (4.2, 55-62)

In addition, the process tested the strength of other aspects of Lynn's identity as a woman outside of the normative path of potential motherhood. Drawing upon these other aspects of her identity during her journey with infertility became a key source of strength and empowerment:

> I never really had that maternal instinct or that need to be a pregnant person. It is really funny because I don't know if that made it easier or harder for me going through this. I think it just made it confusing. I said to a friend of mine, "I feel

> like this would be even harder if I was one of those people that die hard wanted babies because my whole world would have collapsed." If I had always been a little girl that just played with her dolls and could not wait to be a mother, which I very much was not, but if I had been, I just feel like my whole identity would have toppled. But, I kept thinking through this process that there are so many other pieces about me that I am so proud and define who I am in such greater ways, that it is okay that I have this because I have all of these other things to rely on and it is not the defining life characteristic. (4.2, 215-224)

Lynn also retrospectively reflected upon the possibility of exploring more normative paths that she may have previously foreclosed upon, in light of the challenge of balancing life aspirations against the invariant timeline of a woman's ostensible biological clock:

> But, like for me, I feel like I have been fortunate in that I have always rejected the "what you are supposed to do" thing so I haven't really felt beholden to that. (4.3, 607-608)

> …it is interesting now when I look back on that 20 something year old who is very much like *That is not going to be me!* I wonder if I would just tell her to chill out a little bit because maybe what you want changes a little bit as you grow older and the reason why all the aunties and such are pushing for these things to happen is because they want you to experience these joys in life and they are amazing things in life. (4.3, 628-632)

> On the one hand, would I trade what I have done instead? No. Absolutely not. I would want to still be a person who had goals and accomplished things and didn't allow my biological clock or family clock to dictate what I was going to do when. (4.3, 642-644)

> I wish there was a way to reconcile being counter-culture and going against the grain and doing all of those things and follow your ambitions, but at the same time, don't be so closed off to the idea that you may also want the more normative experience too. (4.3, 668-670)

Turning Points

Turning points figured in each participant's narrative as catalytic pivots where either their own perspective or the perspective of others paradigmatically shifted. In Sam's account, the point at which she finally received a definitive diagnosis of Addison's

disease functioned as a turning point for her, her community of support, and the medical establishment's treatment of her condition. Regarding the long-awaited receipt of an accurate diagnosis, Sam expressed the following sentiments:

> It was relief and a sense of well being, a sense of clarity, really. (1.1, 362)
>
> Yeah. It wasn't me against the world. (1.1, 641)
>
> They [friends] were super helpful once it was diagnosed because everyone understands what they are dealing with. (1.1, 622-623)

For Anna, a paramount shift in perspective occurred when she, with the support of her husband and his extended family, began to view the management of multiple sclerosis as a pragmatic matter of logistics:

> It was just like this logistics thing—like, okay, well, this is how we need to do it. (2.1, 244-245)
>
> The turning point was just realizing that it could be something happening to me and not me. (2.1, 264-265)
>
> So then, that is how it was more and then I didn't feel like there was a judgment on me as a person. I didn't feel like I was not a good partner or that he shouldn't be marrying me because of this or that I am a big failure as a person. There was nothing personal about it. Almost by taking care of these things and taking care of myself, that was as valued by people as anything. (2.1, 274-278)

In Emily's experience of living with her visual impairment, a turning point in her perspective of her own disability, as well as disability in general, occurred in the year following her college graduation. In that year, she reached out to the National Federation for the Blind and also began to re-think her conception of disability:

> I reached out to them. (3.1, 662)
>
> That was a big turning point. So that was a year of getting introduced to the blindness community, seeing what the issues are, and accepting the fact that just because I was visually impaired does not make me any more capable than someone who is completely blind. And differentiating between the two really doesn't make a difference. (3.1, 666-669)=

> So like saying that I am legally blind versus blind, it really shouldn't make any difference. We are all in the same boat and that was where I started to think about disability as a very pan term, like disability is disability. If you are visually impaired or you have a learning disability, of course they are all different and come with their complex set of challenges, but at the same time differentiating between them and comparing them puts one above the other. (3.1, 669-674)

> I think it is just a challenge and I started thinking about it in a way that everyone has their own disability. You could be standing next to someone at a bus stop and they could have had 17 different foster homes, or they could have been abused as a child and that is going to affect them and affect their life just as much and it is invisible. That is when I started to think that way. That it is not always as clear as it seems and you shouldn't loop people into—you shouldn't be so judgmental about people or make certain assumptions. I think assumptions is what I am trying to get at here. (3.1, 676-681)

> So, yes, that year I did a lot of soul-searching and probably accepted my own disability… (3.1, 683)

Lynn marked a turning point when she realized that her approach to the "fertility project" (4.2, 518) was not functionally optimal for coming to terms with the conundrum. She recognized that her approach needed to be markedly different from the previous ways in which she had approached problem solving in other aspects of her life:

> I do think that I had blinders on to a certain extent. I was just so compelled to get this fertility project done that I was willing to hurt myself to make it happen regardless of anything else. (4.2, 517-519) I definitely approached it like a puzzle that needed to be solved. (4.2, 523-524)

> I think that part of my big epiphany was realizing that my approach was the wrong approach. I needed to think of this completely different than how I think about every other problem that I solve in my life. (4.2, 561-563)

> So I think that part of the reason why I was pushing and pushing was because I was looking around and not wanting to be left out. Again another part of the epiphany was *This isn't a race. It really has no bearing on my life what other people are up to.* And in some ways, it was hard because you want to be with your friends and be in the same life place and have these things happening to you around the same time so that you can relate. (4.2, 581-586)

> There is—I think that I even said it today—I can't believe that I think it even but, in some ways I am glad that it happened because it created a new dimension of my life that I think makes me a better person. (4.2, 654-656)

Transformation

The leitmotif of transformation resonated through all participants' reflections upon their lived experiences in the context of creating meaning out of those very experiences. Among the transformational changes were an increase in participants' capacity for compassion and empathy for others, including an increased desire and impetus to serve as a resource for others who were undergoing unexpected trials in their life's journeys. The processes of integration and self-acceptance also were highlighted in the broader undercurrent of transformation.

Sam observed that she has more empathy and sympathy for individuals with health issues, being able to understand some of their pain from first-hand experience; she also attempts to be a "source of support and information" (1.3, 53):

> I am certainly more empathetic and sympathetic to people with health conditions. I know what it is like to take medication every day. I know what it is like to learn to have to manage doctors. I know what it is like to be in the hospital. So, I can feel some of the pain when I talk to other people who have everything from diseases to cancer to whatever. I also notice people who have never been sick or hospitalized don't really know how challenging something as simple as outpatient surgery or other "easy" procedures can be. I try and be a source of support and information. (1.3, 48-53)

Anna reflected upon a subtle self-transformation. This transformation has involved the gradual integration of her condition into her self-identity, leading to enhanced self-acceptance. Anna also noted an increased equanimity regarding how she has learned to manage the logistics, including information management, of her illness and its vicissitudes:

> Maybe I am just growing up or something, and just becoming more comfortable with who I am. (2.3, 143)

> I guess maybe things will just get more and more manageable and feel better and better and maybe just less intrusive. Maybe that will even be not necessarily the disease changing, that will just be me growing up more and me integrating it more or me telling people more, or maybe just being okay not telling people more, just getting better at that. (2.3, 173-177)

> It is definitely making more sense how this all fits together. It will be interesting to see where to go from here because I do feel like I could be more proactive now. As far as managing the disease, that is all fine now. That is all good. But in managing its place in my life, like within my relationships or within the workplace and it may be that, you know, I was wondering if I am going to end up telling more people, but it may just be that I become more comfortable with the fact that I don't have to tell people. I felt that way at work this week. I felt like it is okay and I don't have to tell. I just didn't feel so overwhelmed by it. (2.3, 379-385)

While she is still optimistic, Emily has reached the point of living her life as if there is no immediate cure for Stargardt's Dystrophy. This perspective is in contrast to her previous perspective about a future cure in the time period right after her diagnosis:

> So, there is no cure, I should also mention that too, I never say not yet. I try not to say not yet because in my mind, so what if there is never a cure. I lived for a long time, living like there was going to be a cure but now I am living that there is not and if there is then that is just an added bonus. (3.1, 864-867)

> But when I was diagnosed they were saying there is going to be a cure in 10–15 years and it has been over 10 years, so miracles are happening every day, but it's not what I want to use as a fall back which is what I did for a long time. I think it's also for people to say *Well there may be a cure someday.* I feel like they are not accepting me as I am at the present. It's good to remain hopeful – it is. But I think people need to recognize too that they need to be comfortable…I need certain people in my life to be comfortable with the fact that this is not going away. (3.1, 871-876)

In addition, Emily expressed the lessons she has learned, through her own journey in living with her disability, of the importance of not resorting to stereotypes or judging others based solely upon surface, superficial appearances:

> I have learned through this that things are not always what they seem and you shouldn't assume that just because someone is behaving a certain way that there aren't hidden disabilities or hidden reasons behind that. So, I've learned. That is something that this has definitely taught me that I wish more people thought this way. Things aren't always what they seem. Don't assume and don't be so quick to stereotype and so quick to judge. Usually there is a good explanation or a good portion of someone still there to explore. (3.3, 445-450)

Lynn's personal volte-face involved a number of aspects. These aspects encompassed a growing openness to share her story with others as one way of being a helpful resource to others, as well as heightened sensitivity, compassion, and alacrity to assist others experiencing challenges and trials, trials not solely limited to the challenge of infertility:

> …part of this for me has been about talking about it and making myself open to other people and being comfortable with sharing what it was like and how we got through it. Now, I feel like I have people in my life who are on the other side and just starting the journey and I am equipped to be a resource for them. I wouldn't be able to do that unless I was open and honest about what has been going on. That feels really good to be able to do that. (4.1, 908-912)

> About anything in anyone's life whether it be something they are dealing with that is challenging or difficult. I am much better now at connecting with that and knowing how to talk about things in a sensitive way but also, just having that open mindedness that not everyone is on the same track. I wouldn't say that I was close-minded before, but I have lived it and I can connect to it. (4.2, 642- 646)

Lynn has observed a change in how she more openly acknowledges difficulties or adversity being experienced in others' lives, along with a willingness to make herself available to those who are experiencing challenges:

> I think in the past I felt like I wouldn't address it or I wouldn't acknowledge it because I thought that was better. Now, I know, that it is such a better approach to make yourself available for whatever that person needs whether it is talking about it or not talking, but just so that they know you are there and that you are someone who is ready to listen. It is a subtle shift in how I deal with when someone is having a difficult time, so I do think that it is this journey that has taught me how to do that because I've felt it when people do that for me and I have had the opposite done for me and I know which feels better now! (4.3, 175-182)

> …people who would just say things like: *If you want to talk about it we can talk about it. If you don't, we don't have to, just let me know*. Just that simple statement is very powerful, and I find myself just making myself more available to hear what other people have to say, and I think it has allowed me to be more open. It works both ways; it allows me to be open about what I am going through and it has allowed them to feel like they can share and be open with me so it has been a useful process for me to go through. (4.3, 186-192)

Lynn also noted an increased capacity for self-introspection that resulted from her journey with infertility:

> I don't think that I was a very introspective person to the depths that I am now. (4.3, 498-499)

> I do feel grateful for a reason to introspect. It is one of the only opportunities that I can think of in my life where I have been—I don't want to say forced, but forced is kind of the right word—forced to think about some really tough stuff about myself and my life, my relationships, that I don't think I would have done otherwise. (4.3, 510-513)

> I also tend to be analytic, but I don't think I would have gone to the levels that I have gone to had it not been difficult. (4.3, 537-538)

Redefining Disability

All participants shared reflections upon whether or not they considered their respective conditions to be a disability. Sam did not consider her chronic illness of Addison's disease to be a disability, as it does not adversely impact her on a daily basis and as it remains very manageable with daily medication:

> I do not. I think if it had more of an impact every day—hard to say when you don't have a disability to say what it would be like to have a disability—but my perception is that if I was diabetic or if I had something that impacted me negatively every day, I would call that a disability. I don't consider taking medication every day a disability. (1.3, 75-78)

> If you are like me and sort of forget about it until something isn't right—not even life-threatening—but even forget about it until your medication needs to be adjusted. So, I can go, if everything goes fine, almost a year without really having to think about it. Yes, I have to go pick up the medication. Yes, I have to take it, but if I am only getting the levels tested once a year, it is just not that impactful. (1.3, 315-319)

In contrast, Anna considers her condition of multiple sclerosis to be a disability due to its chronic nature without an extant, definitive cure:

> Yes is the answer—I do consider it a disability. (2.3, 59-60)

> But, I am not sure how the finality of the diagnosis and the pretty certain idea that it will be a lifetime condition that it is not going to get a cure or something, it can be manageable, like we talked about, but I am going to have it forever. So, I think that might be a piece of what makes it feel like a disability. (2.3, 64-67)

> …somehow I feel like the chronic-ness of the MS makes it more of a disability in the term. I hope that doesn't sound like I think I am better than anyone else or something… (2.3, 70-72)

> I definitely feel like the word disability fits for me. So, even when we first met, or even when I was hearing about your research, I was like, *I want to do that.* So, I definitely identify with it and with the invisible part of it. Even when I am feeling well, it feels like I have got this. It doesn't necessarily feel like a bad word. I don't mind it. It doesn't make me feel bad or anything. I think probably because it affects all of life. (2.3, 80-84)

In contrast to her initial feeling following diagnosis that her body was attacking her internally, using the metaphor of alien or foreign material, Anna expressed that her illness could now be represented as naughty pixies or leprechauns, rather than aggressive, amorphous aliens:

> I feel like the goo is gone. I feel now like it is more like tiny little pixies, like little fairies, and mean fairies are like every so often messing with something—a naughty little leprechaun. It is something that is not bad, but a cute little thing, but it is messing. (2.3, 159-161)

Emily, who considers her visual impairment to be a disability, has actively endeavored, through educating others, to deconstruct existing stereotypes around disability. The ongoing process of educating others about disability also connects to Emily's skills in self-advocacy, allowing her to create novel spaces to better exercise agency for herself and for others with disabilities:

> I say that I am just like anybody else and everyone has their own disabilities and it shouldn't be considered amazing. I don't say this, but it is my own personal thought, that I don't think it should be considered amazing that a young professional can operate and live an extremely independent and happy life with a disability. That shouldn't be amazing. That should be very standard. (3.2, 186-190)

> I let them come to me with questions and then, once they start asking questions, I try to take them down a path to learn even more because I think that sometimes asking questions like that, they think is uncomfortable for me or they think it is insensitive, but I actually enjoy it because I just assume that they assume that either a) I can do it like a normal person or b) that I can't do it at all. They don't understand the in-between. How I operate. (3.2, 205-210)

As a young person with a disability, Emily has observed that disability is a fluid term:

> I think knowing one's background plays into how their disability affects their life. Really, when I think about disability, I think of it as just a challenge that sets you apart in the sense that it makes you a minority. I think about the term disability as a very fluid term. Yes, I absolutely 100% think that I have a disability. I am legally blind and because of that I consider it a label and a part of who I am, but also without my vision loss, I would not be the person who I am today. I don't know if I would be someone different. I would still be me, of course, but my life would be completely different. I can say now that I am really glad that it is not and that I am happy where I am in my life. I feel so fortunate to be in a place where I am comfortable saying that. (3.3, 45-52)

Emily also noted that disability still remains "a loaded term" (3.3, 77) associated with stigma:

> It is such a loaded term as we have discussed before and people who even have disabilities themselves don't necessarily consider themselves disabled because it is such an icky term associated with poverty, with being uncool if you are a younger person, or with elderly, that it just has very historical prevalence that eventually, hopefully, will become a more accepted term and with less stigma but for now, I think it still has that. (3.3, 77-81)

Emily expanded further upon her own definition of disability, as well as her insights on and perspectives of disability as a fluid term where disability is a spectrum:

> So, for me, how I would define disability—to say someone is disabled—it could be temporary; it could be permanent; but for whatever they are in that moment or

> time, they are dealing with a challenge that puts them in the category of being a minority. So, it is a very unique challenge that requires them to adapt to an environment that is not all the time suited for them since they are in a minority. It just forces them to adapt and do things a little differently. Now that could be—it is a very broad and general term—so that could be someone in a wheelchair has to use a ramp. Someone who has dyslexia has to listen to books on tape because that is what helps them. Someone who is having knee problems or needs knee replacement, they have a temporary disability; they have to use a cane. Someone who has autism obviously perceives this world in a very different way. (3.3, 83-91)

> It is a spectrum. I think that is one of things that people miss out in terms of disability is that they don't realize that it is a spectrum. They think it's a concrete, permanent label that's attached to you that means something X, Y, Z that is not going to change. One thing that I have always said is that I can do most things that anyone else can do, I just do it a little differently and it doesn't make it better and it doesn't make it worse. (3.3, 92-96)

Emily observed that individuals tend to default to the "hindrance rather than the empowerment of having a disability" (3.3, 104) with a focus on immutable deficits in ability, rather than fluid differences in ability:

> I think that people also miss out because disability is a very negative term. It is not having the same ability as someone who is "normal" whatever the heck that means. So, I think people often forget the positives of having a disability which range from being a good problem solver to being forced to overcome a challenge and the positives that can come out of that. People immediately go to the hindrance rather than the empowerment of having a disability, if that makes sense. (3.3, 100-105)

Lynn also considered her condition of infertility to be a disability, particularly in light of her age at the time she was given the diagnosis:

> I do consider it to be a disability for the reason that to me it has felt very much like my body has not been able to do what other female bodies can do very naturally and I don't know what the clinical definition of disability is or anything like that, but it certainly has felt disabling to have this condition. It has felt unbelievably invisible at times, so I was thinking a little bit about this idea of a disability and I think maybe the reason why infertility is kind of contentious in terms of being labeled as a disability is the age issue, so there is a point at which by natural and biological processes we all will be infertile just because of nature. So, I think that may be where that grey area comes in and I feel like I have always looked around at women my age and felt like the age factor didn't feel

> central because I felt like other women my age were easily achieving pregnancy with no interventions, no assistance. (4.3, 6-15)

Lynn highlighted the factor of age as the primary conundrum in her overlapping journeys with fertility and infertility, given that she was only 32 years old when reproductive challenges first began to surface:

> So to me the whole age explanation doesn't fit well. I have always thought that there has to be something else to help explain it or maybe it is that there is such a grey zone. It has always felt to me like a completely arbitrary and random thing that I just happen to be the one out of however many women that just can't do it without help. (4.3, 23-26)

> …so in that way it just felt very much like a disability. I am not able on my own to achieve something that is normal. I guess that answers: Is it a disability? For me: Absolutely. Yes and I continue to think of it that way as I move forward. I still feel very much like it hasn't left me… I feel like it will stay with me. (4.3, 30-34)

> Like I have said before**,** I think it has become part of my identity and part of who I am. I am weirdly part of this club of women who have kids by all of these alternative pathways. (4.3, 40-42)

Hopes and Aspirations for the Future

Participants generously shared their hopes and aspirations regarding the future of living with their respective conditions. These aspirations were not just for themselves, but also for other women living with hidden illnesses or disabilities.

Sam re-visited the verisimilitude of "an absolute train wreck" (1.3, 105), including dismissal by many members of the medical establishment about the validity of her symptoms that characterized the protracted period leading up to her diagnosis of Addison's disease. She expressed a hope that there would be more accurate data available in the future, as well as increased training, for members of the medical establishment to facilitate an accurate, expeditious diagnosis of Addison's disease in individuals presenting with the initial symptomology of this rare disease:

> …my story of diagnosis is very similar to a lot of people's stories of diagnosis with Addison's disease. It is usually an absolute train wreck that verges on major catastrophe and it would be great to have endocrinologists and doctors in general more knowledgeable of the disease, but again, there are thousands of rare diseases and it is probably unrealistic to expect doctors to have knowledge of all of them and it know what symptoms to look for. Certainly my wish would be that people could, step one, get an accurate diagnosis. (1.3, 104-109)

> There are stories of people trying to get diagnosed for years. They can just never find anyone who can figure out what the real problem is and the problem is the symptoms are so common to so many other things—weight loss, vomiting—it could be anything! So, certainly, I would hope that there would be more awareness and training… (1.3, 110-113)

Anna expressed a hope, both for herself and other women with invisible illnesses, that one could achieve a sense of congruence and satisfaction in one's life:

> So, for hopes for the future, I would hope that my lifestyle will fit with my ability and it will even out and I will just be content with the balance and that is what I hope for all of the women too. (2.3, 97-99)

> I guess maybe your satisfaction with your life. What you want your life to be and what it is. (2.3, 106-107)

> I feel that my fit now is good. Part of why it was interesting to go back to the very beginning of one of my priorities—my priority I think is more on feeling good and not accomplishing a lot. (2.3, 119-120)

Anna also articulated a hope for an increased sense of wellness in terms of embodiment and a healthy lifestyle balance in light of gendered norms for women:

> I just hope that they would find a way to feel better similarly, I guess, just technically, physically with the disease—better. Hopefully more medicines come out or more treatments come out or more things come out that will really help them to not feel all of the crummy symptoms because I think most women with MS are having something or other going wrong all of the time. (2.3, 222- 226)

> In their body. So, I hope all of the research can help fix that for them (2.3, 230)

> And they can find a way to find a life/body balance—to live the life that they want to lead and the woman stuff—to have a family or to have a job or not have a job. To do whatever that role entails. (2.3, 232-234)

Anna's counsel to other women with MS was a gentle exhortation to come to terms with the condition and then to move forward in creating a life that they each would personally define as fulfilling:

> Accept it and be positive and it will be okay. Then, be successful and fulfilling in what you want for your life. As it relates to the MS, it is really just a matter of dealing with it as a disease and as a disability however you want to. Of course, these are things that I hope for them anyhow, but as it relates to the MS—really get a grip on it, get a handle on it. (2.3, 329-332)

Emily's hopes and aspirations for herself comprised a hope for meeting future challenges with the same confidence and support system that she currently has. She also articulated an aspiration to continue to advocate for herself and others while deconstructing vestigial, negative stereotypes of disability:

> For myself, I think that as I lose my vision or as I continue down the road to have different life experiences because I know that I will encounter new challenges as time goes on, that I meet them with the same support system and with the same confidence level that I do now. As I lose my vision, I don't want it to give me any added fear or anxiety—that I still remain self-confident and always continue to advocate for myself and for others and be a positive role model for not just people with disabilities but for the general public to show that disability doesn't have to look like the picture in their minds, that it can look like me. I consider that a very positive thing. (3.3, 234-240)

With regards to aspirations for other women living with Stargardt's Dystrophy or other hidden disabilities, Emily expressed a similar sentiment as Anna, namely a hope that others will come to accept their condition, whether it is temporary or permanent. In addition, she articulated a hope that others will summon the courage to meet future obstacles, including others who might be challenging, with optimism:

> I think for aspirations just: 1) That they come to terms with it and that they accept it whether it is permanent or temporary. That is doesn't change who they are at the core and if it does, it increases their confidence within themselves that they are able to adapt and overcome and that they are the same person despite their challenges. And to be able to have the self-awareness and ego that they are

> [the same person] despite being "challenged" (but I don't like that word)… (3.3, 294-298)

> So, that they have the courage to meet people that challenge them and they have the courage to either educate them, or to let them roll off their shoulders and then to move on, to recognize that you can't educate and you can't convince someone of your attributes always. (3.3, 313-316)

> I wish that people no matter what walk of life they are, that they are able to meet the challenges that present themselves and to remember that there is always a silver lining and there is always—even though it may not make sense then and there—that eventually it will. I am not saying that it will ever make sense; I am just saying that you will find your reason to justify and then keep on trucking. (3.3, 463-467)

Lynn expressed the hope for herself that she can continue to move into the future with positivity and with the integration of her post-diagnostic experiences into her self-identity, without necessarily having the diagnosis solely define her. In addition, Lynn spoke to her hope that she retains the increased capacity for compassion and empathy that her journey with infertility has catalyzed:

> …my hopes and aspirations for my own process are that I can continue to be in what I feel to be a very positive place for it. To be in a place where I am comfortable with it, where it is part of who I am but not a defining part of who I am in that I don't lose touch with that sensitivity that it has brought out in me. (4.3, 123-126)

> So, not only being able to see it when other people are struggling but just the ability, like I was saying in our last talk, the ability to really make myself available to any sort of difficult situation that falls outside of the norm**.** To be able to be supportive of people regardless of what life circumstances they find themselves in. I don't want to lose that. I don't want that to go away because when you are talking about meaning and I think it is the silver lining in all of it. It is the piece that has really taught me so much and yes, of course, there is pain and there is suffering, but it is now to a point where I can really be helpful (I don't know if helpful is the right word.) but I can be a support to other people. (4.3, 126-133)

In light of Lynn's hopes and aspirations for other women who are experiencing infertility, she first expressed the hope that other women would never have to confront such a challenge in the future, although her own experience was self-transformative:

> I just feel that I don't really want anyone to have to go through this. (4.3, 198)

> Also that it has brought out really good things in me and yet I don't want anyone else to have to live through it. It is this funny thing. That was awful and I don't want you to have to deal with that even though I am sitting here saying that it has actually taught me a lot and it has been really good for me. (4.3, 204-207)

In the context where infertility still exists as a diagnosis, Lynn expressed a hope that women would have the privileges of a supportive environment, as well as space to undergo the work that is involved, physically and emotionally, with addressing the diagnosis so that women's self-image is not adversely impacted:

> But while it [infertility] is still around and while women are still being diagnosed with it, what I would hope for them would be to have a supportive environment where they are able to go through—like there is some journey that you have to be able to go through while you go through this and it is a lot about reconciling these societal disconnects in your own life with how you internally feel about the place that you are at and how the diagnosis chips away a little bit at your self-esteem or self-image. (4.3, 231-236)

> What I would ask for would be space for women to be able to undergo that work because it is really hard work and we are just expected to march along and in some ways, the medical system as it is set up right now, just puts you on this track of treatment and doesn't incorporate any real way of addressing the very important psychological parts. (4.3, 238-241)

In light of her own experience, Lynn also addressed a hope that the current reductionist model of the medical-health-care system in treating infertility could be changed in the future to more holistically address a woman's whole body, rather than focusing solely upon one or more reproductive organs.

> There should be more support woven in to the normal care that women are receiving during this process. (4.3, 249-250)

> I mean like when they are going through these various forms of treatment, as a part of that, you have a support group or you are involved with a therapist or you are in counseling. (4.3, 254-255)

> If I had been exposed to that, it would have been really good for me to hear other people saying: This is my story . . . it just would normalize it in a lot of ways. It would have pushed me quicker into the good parts of it and maybe shortened the amount of time where things felt miserable. We don't have to get into a dissertation about the healthcare system. (4.3, 283-287)

> I think about it a lot of times, and it just felt like I was out swimming by myself and that is not the best thing for people to be doing. (4.3, 298-299)

From Lynn's perspective, the narrow parameters that define success in infertility treatment potentially need to be changed and expanded to address mental and emotional health:

> I also think that there are other outcomes that we need to think about. We need to think about the quality of life and mental health, and all of these other things that really suffer as a result of this condition, that are a huge drain on people's lives and if you want to talk dollars and cents, on our productivity. I think it is not unreasonable to think that it should be part of it. (4.3, 308-312)

> I think that thinking about what these words actually mean and boiling that down to something that is a medical diagnosis, I don't think is super easy to do because what does it mean to treat a woman with infertility. Again, is getting pregnant the fix? I don't know. What is the goal? The goal for the medical system is to get the woman pregnant—the biological disability and making her able to do it. But, I don't know that it is successful at addressing all of the other pieces that go along with being "infertile." (4.3, 360-365)

As Lynn observed, a diagnosis of infertility impacts not only the woman being diagnosed, but also her primary relationships and her community:

> It is your relationship with your partner if you have one. It is your relationship with your family members. It is your relationship with your friends. It is your interaction at work. It is your place in your community. Everything suffers as a result of this and I think to ignore that is really short sighted. To just treat ovaries is totally missing the context within which people are struggling with this condition, and I think it is really unfortunate. It is part and parcel of how I think that the healthcare system works in general. We treat this illness. We treat this condition. It is a very narrow way of looking at it. (4.3, 319-326)

Expanding her hopes and aspirations to include all women and women with hidden disabilities, not solely women who have been diagnosed with infertility, Lynn articulated the hope for "a more contextual way of approaching a disability" (4.3, 345):

> I think that what I am talking about is such a more contextual way of approaching a disability or a condition like this. We do a really bad job at managing all of the things that go along with an illness or a disability**.** We just try to fix that one thing and expect all the rest will fall into place once it is fixed and I just don't think it's the most effective. (4.3, 344-349)

Lynn also reflected upon the possibility of raising the discussion at an earlier stage with young women regarding fertility management, a topic under the purview of such areas as adolescent medicine:

> …it makes me think that the age part, that is a curve ball. There are still women who go through this, and it is totally not age-related and even though I am telling my younger self to think about this earlier, I still could have come out with having this problem. (4.3, 721-723)

> Maybe that is another hope and aspiration for the next generation, is like, how can we make this part of a conversation that happens fifteen years sooner—not the lecture one you've already crossed your 30th birthday or your 35th birthday. So that it doesn't have to feel like you are being yelled at down the line and that you've made this big mistake. (4.3, 729-733)

Research Question #2: Summary

In summary, participants elaborated upon a tapestry of meaning-making woven of different threads. These threads carried these following themes: (a) reflections on philosophy of living; (b) turning points; (c) transformation; (d) redefining disability; and e) hopes and aspirations for the future for themselves and others. Thoughtful pragmatism with tempered optimism was a shared motif among all of these themes. In particular, participants spoke to the transformational impact of living with an invisible, hidden condition. Participants also expressed optimism regarding the future for other women with hidden conditions and disabilities in the context of voicing

recommendations for potential systemic changes. Some of these systemic changes included rectification of observed lacunae within the traditional medical-health care system of diagnosis and treatment, along with social changes in deconstructing stereotypes of disability.

Summary of Chapter Four

In summary, participants articulately gave voice to their lived experiences of living with hidden chronic illnesses and/or disabilities. While the story shared by each participant was uniquely personal, infused by their individual journeys of living with their respective conditions, some prominent, common motifs emerged among the broader exploration of inclusion, marginalization or exclusion, embodiment, and meaning-making.

In terms of experiences of inclusion, a common leitmotif shared by all participants was the importance of self-advocacy in transforming a situation or experience of marginalization or exclusion into one of inclusion. In addition, the majority of participants also addressed the role of passing, or non-disclosure, of their condition in certain contexts, particularly professional contexts. For a few participants, technology, as a material factor, played a role in enhancing their experiences of inclusion.

With regards to experiences of marginalization or exclusion, a shared theme was the unexpected role in which the medical-health-care establishment played in contributing to feelings of isolation, marginalization or exclusion, particularly in the time period preceding participants' receipt of their respective diagnoses. A second leitmotif that figured in participants' narratives was the sense of marginalization or exclusion that arose as a result of the invisibility of their respective conditions, often compounded by

others' lack of awareness, knowledge or understanding about their conditions or disabilities. Finally, the material factors of gender, age, and economics also functioned to contribute to participants' feelings of disenfranchisement.

Participants' experiences of embodiment encompassed actions and strategies, such as self-care, for pro-actively managing the physical aspects of their respective conditions. Such strategies helped to militate and obviate negative symptoms, such as pain, which was invisible to others. For a few participants, the combined material factors of gender and technology also played a role in their experiences of embodiment.

Finally, with regards to creating meaning out of their lived experiences, participants composed a nuanced tapestry woven of some shared threads. These threads carried the following themes: (a) reflections on philosophy of living; (b) turning points; (c) transformation; (d) redefining disability; and e) hopes and aspirations for the future for themselves and others. A powerful motif in this tapestry was participants' expression of the transformational impact of living with a hidden condition or disability. Participants also expressed pragmatic optimism with regards to their hopes and aspirations for themselves and for others, including observations about systemic changes that could be helpful for others in militating against the challenges they themselves had experienced in their own journeys. Some of these potential systemic changes are highlighted in the next chapter.

CHAPTER V

CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Summary of the Study

This qualitative study explored the lived experiences of inclusion, marginalization, and exclusion in the lives of women who have a permanent, non-visible (hidden) disability. It also explored the corporeal dimensions, such as issues of embodiment, of the lived experiences for women with hidden disabilities. Finally, this phenomenologically based study examined how women with non-visible, hidden disabilities articulated the meaning of living with an invisible disability.

The study utilized a phenomenologically based approach that incorporated in-depth interviewing, as described by Seidman (2006, p. ix). Participants were four adult women who resided in the U.S. and who were diagnosed with a long-term disability or chronic illness. The respective diagnosed conditions of each participant consisted of the following: Addison's disease, multiple sclerosis, Stargardt's Dystrophy, and unexplained infertility.

Each participant engaged in a series of three interviews, each of which was a maximum of 90 minutes in length. These three interviews consisted of the following: (a) a first interview that centered around a focused life history of the participant, (b) a second interview that focused upon the details of the experience and contemporary experience, and (c) a third interview that involved the participant's reflection on the meaning of her experience (Seidman, 2006).

Conclusions and Implications

Introduction

In this final chapter, primary conclusions and implications are drawn by connecting primary findings from the study, as presented in Chapter 4, to previous findings as reported in the literature, which were presented in Chapter 2. Following the presentation of conclusions and implications, recommendations for future research and future practice are addressed.

Women with Hidden Disabilities

The results of this study illuminated the mainstream assumptions and presumptions that continue to challenge full participation by women with hidden disabilities in contemporary social structures. These mainstream presumptions are those that critical disability theory has sought to actively interrogate, including the following: (a) the language used to frame concepts of disability; (b) contextual politics surrounding different conceptualizations of disability; and (c) philosophical challenges informing different constructs of disability, such as passing as able-bodied by those who are not visibly disabled (Devlin & Pothier, 2006).

With the additional layer of a material feminist lens, this study also illuminated normative, social constructs of gender that negatively impacted complex issues of identity and ontology for women with hidden disabilities (Alaimo, 2008; Hekman, 2010). Results thus further contribute to a "feminist understanding of bodily suffering" (Wendell, 1996, p. 166) as participants spoke to feminist concerns including the status of embodiment and the lived body, the medicalization and reduction of the body by the medical-health-establishment, the social construction of identity, and the cultural primacy

of normalcy, which informed such phenomenon as passing. Key findings of this study with regard to passing, legitimacy, and embodiment are briefly highlighted against the broader context of the literature in the following three sections.

Passing

Samuels (2003) observed that unwarranted social condemnation of passing, namely the behavior of passing as non-disabled, by the normate or societal mainstream tends to conflate two different aspects of passing for persons with non-visible disabilities: passing deliberately versus passing by default. For individuals with non-visible conditions, it is thus possible to simultaneously pass by default (i.e., the condition is hidden by default) as well as with intentionality (i.e., deliberately choosing non-disclosure). Because of the non-visible nature of their respective conditions, all participants in this study could pass by default in most contexts.

Three out of the four participants in this study chose to pass (e.g., choosing non-disclosure of their respective conditions) in their professional work environment. In the case of non-disclosure in work or professional contexts, which is the choice that Sam, Anna, and Lynn all volitionally made, such passing could be viewed as "a valid strategy for negotiating certain situations" (Samuels, 2003, p. 240). In particular, for Anna, it was a choice that she made only after experiencing marginalization and exclusion after coming out about her diagnosis of multiple sclerosis in previous work environments. In Sam's case, the ubiquitous lack of public understanding, awareness, and knowledge of Addison's disease, which is a rare disease, was a contributory factor in her decision not to disclose information about her diagnosis across different contexts. As Sam observed:

> Again, no one knows what it is and they don't have time to create perceptions and that is frankly why I don't bring it up. What is their response going to be unless it is somehow relevant to the conversation and sometimes it is but not very often. 96 (1.1, 705-707)

Emily volitionally selected to disclose the facts about the progressively deteriorating condition of her visual impairment and legal blindness, secondary to Stargardt's Dystrophy, in both job interviews and her work settings. As Samuels (2003) observed, "it takes tremendous chutzpah for nonvisibly disabled people to assert our disabilities in public settings or to ask for accommodation; denial, mockery, and silent disapproval are some of the cultural mechanisms used to inhibit us" (p. 242). Even with Emily's forthrightness and open communication to her work colleagues about her central vision loss, she was faced with the ongoing challenge at work of having to remind the majority of her colleagues about needed accommodations. As Emily noted, "I think that they just forget" (3.2, 266-267) about her visual limitations as she does not yet use a white cane as an iconic marker or symbol of legal blindness. The necessity for Emily to continually self-advocate, specifically to communicate and request accommodations in her work environment, "reflects the dominant culture's insistence on visible signs to legitimate impairment" (Samuels, 2003, p. 245).

Lynn's recollection of early experiences of marginalization following her diagnosis encompassed strategies for pro-actively managing such marginalization through two additional forms of passing raised by Gillespie (1996, p. 102). Gillespie (1996) highlighted three forms of passing: selective avoidance of certain categories of people, selective avoidance of certain categories of situations, and self-deprivation. At particular points during the course of her journey with infertility, Lynn selectively avoided both certain categories of people as well as certain categories of situations, such

as baby showers, which could be emotionally challenging. Lynn described this behavior thus:

> In some cases, I even avoided certain people because I felt like I didn't want to talk to them about it for whatever reason and so there were definitely things that I didn't participate in because it felt like too much to me. The classic example of that is the baby showers. (4.1, 500-503)

Legitimacy

The issue of passing is directly related to the hegemony of visibility in normative culture. In turn, the hegemony of visibility directly informs issues of legitimacy for individuals with hidden disabilities (Samuels, 2003, p. 245). The issue of legitimacy was a prominent leitmotif in Sam's acutely marginalizing experiences with the medical establishment prior to her diagnosis of Addison's disease. Sam's interactions with the medical establishment prior to and following her diagnosis add further weight to the findings of Vickers (2001). Vickers specifically highlighted the influence of the medical profession in the lives of women with unseen chronic illness:

> All of the women interviewed included discussions about the influence of the medical profession over their lives with chronic illness, even their work lives…Readers should understand that I did not set out to explore experiences with the medical profession, believing it initially to [sic] beyond the scope of this research. However, time and again my respondents, without my prompting, kept returning to these issues, prompting me to reconsider their importance. It would seem that the place of the medical profession is inextricably woven into the lives of these women, including their working lives. (para. 22)

The experience of marginalization that Sam described in the chronicle of her protracted, non-linear diagnosis of Addison's disease, namely that it was akin to "an absolute train wreck that verges on major catastrophe" (1.3, 105-106), contained themes which were also resonant with the findings of Taylor (2005). Taylor investigated the experiences of adults with chronic fatigue syndrome (CFS), most of whom were female.

Similar to the pre-diagnostic experience of Sam with Addison's disease, the participants in Taylor's study also reported experiences with health care providers marked by "lack of validation of participants' described impairments and symptoms, lack of knowledge about CFS….[and] tendency to overemphasize psychological and social variables as possible causes of the symptoms." (Taylor, 2005, p. 501) In addition, another theme common to Sam's lived experience with Addison's disease and the participants with CFS in Taylor's study was the reported difficulty in "viewing themselves as disabled, much less as members of an oppressed disability community" (Taylor, 2005, p. 503).

However, unlike the participants in Taylor's (2005) study, Sam was able to obtain a sense of "relief and a sense of well-being, a sense of clarity" (1.1, 362) once she obtained a diagnosis of Addison's disease. This concrete diagnosis also proved helpful for Sam's community of support, as it provided concrete data that functioned as a lodestar by which Sam's friends and family could steer in offering and providing support. In contrast, the participants in Taylor's study reported ongoing lack of validation for CFS as a legitimate medical condition, along with ambivalence regarding their impairments from friends, family, and professional colleagues.

Legitimacy was also an issue for Anna in her workplace immediately following her diagnosis of multiple sclerosis. As Anna recounted, "I had to take time off of work and my work situation also wasn't the best. I remember them giving me a hard time. But, it was like, I can't see. I can't work!" (2.1, 69-70) Anna's initial challenges in the workplace following her diagnosis of MS are similar to the findings that Sturge-Jacobs (2002) reported in her phenomenological study of women with fibromyalgia (FM). Sturge-Jacobs reported the following:

> The stress of dealing with an invisible disability added to the frustration and anxiety for each of these participants. The dilemma of how well they looked in relation to how unwell they felt was a cause of conflict, not only for themselves, but also for other family members, friends, physicians, and employers. Inability to meet previous expectations and to act as "before" was most frequently met with negative statements and unfriendly looks. After all, they looked the same. (p. 29)

In addition, Anna's later experiences with managing physical symptoms that were completely invisible to others, such as pain or numbness, were also experiences reported by the participants in Sturge-Jacobs study. However, in contrast to women with FM who experienced constant pain, Anna experienced vicissitudes in pain and numbness depending upon environmental factors, such as extreme heat.

Embodiment

In terms of embodiment, two of the participants' experiences, namely Anna's and Lynn's experiences, reflected an insight shared by Zitzelsberger (2005), who examined the experiences of women with congenital physical disabilities and differences, differences that were visible in some contexts:

> Participants' stories indicated that they struggled continuously with powerful and colonizing hegemonic gendered norms of the appearance and capacity of bodies. Yet, each woman also experienced moments of seeing differently through resistance to hegemonic orderings of normal/ abnormal, beautiful/ ugly, and same/ different bodies. As such, they have come to see their bodies within and also outside of these normative and idealized representations. (p. 399)

In their personal, lived journeys with their respective conditions, both Anna and Lynn worked against "the powerful and colonizing hegemonic gendered norms" of the capacity of bodies (Zitzelsberger, 2005, p. 399). Similar to the female participants in Zitzelsberger's (2005) study, Anna and Lynn also "rejected the ways they are seen through hegemonic cultural discourses about disability and difference" (Zitzelsberger, 2005, p. 398).

As described in the previous chapter, Anna used a visual metaphor of endogenous, alien material internally attacking her to describe the initial phenomena occurring within her body during the time period following her diagnosis of multiple sclerosis (MS). Anna's pivotal turning point in learning to regard the MS as merely logistics to be managed also catalyzed a shift in her self-perception of her embodied experience. With this transformation of her internal perspective of her illness came a concomitant transformation in her view of her embodied experience. Anna now regards her MS as being akin to naughty pixies or leprechauns, rather than amorphous, hostile alien material:

> I feel like the goo is gone. I feel now like it is more like tiny little pixies, like little fairies, and mean fairies are like every so often messing with something—a naughty little leprechaun. It is something that is not bad, but a cute little thing, but it is messing. (2.3, 159-161)

In her experience of embodiment, particularly in relation to gendered expectations regarding reproductive capacity, Lynn consciously worked to transform an initial, normative perception of "feeling like I am failing in my job as his female partner to provide a baby of his genetic make-up and my genetic make-up" (4.2, 157-158) by actively questioning the normative path typically prescribed and transmitted to women via sociocultural norms. Through this active resistance, Lynn reached a point where she could draw upon other extant strengths and capacities in her overall identity to provide a counter-narrative to the hegemonic narrative of a woman "as a vessel" (4.2, 234), wherein a woman's identity is solely connected with her body's reproductive capacity:

> But, I kept thinking through this process that there are so many other pieces about me that I am so proud [of] and [that] define who I am in such greater ways, that it is okay that I have this because I have all of these other things to rely on and it is not the defining life characteristic. (4.2, 221-224)

Lynn's questioning of gendered social norms thereby assisted in her deconstruction of "the power dynamics inherent" in "regulatory cultural codes of femininity and ableism" (Westhaver, 2000, p. 95), allowing her to gain new clarity in navigating the uncertain terrain of living with unexplained infertility.

The embodied experiences of Anna and Lynn in living with their respective disabilities support the view of Shakespeare and Watson (2001). Propounding that it may not be possible to easily demarcate where disability begins and where impairment ends, Shakespeare and Watson argued for dismantling the dichotomized view of impairment and disability with a view towards integration. Additional exploration of the nexus between impairment and disability follows in the next section.

Redefining Disability through Lived Experience

The results of this study further revealed the liminal space between the antipodes of abled versus disabled, providing further support for the germinal concept of a spectrum or continuum of ability. All participants touched upon the motif of redefining disability in their reflections upon meaning making in light of their lived experiences with their respective, non-visible conditions. As Do and Geist (2000) observed regarding alterity:

> Everyone is othered to some extent; we all possess disabilities, whether visible or invisible. Trans-formation implies communicating new messages that resist stereotyping and othering. It is not a process that is negative or positive, good or bad; rather it is a process of finding a personal middle ground between extremes through inventing and reinventing one's identity. Importantly, persons who are abled or disabled can be part of the transformations that communicate embodiment. Along with breaking away from the label of the "silent majority" comes the redefinition of disability. (p. 60)

Emily's definition of disability, informed by her own lived experience of living with legal blindness and progressively deteriorating visual acuity, casts disability "as a very fluid term" (3.3, 47).

> I think that is one of the things that people miss out in terms of disability… is that they don't realize that it is a spectrum. They think it's a concrete, permanent label that's attached to you that means something X, Y, Z, that is not going to change. One thing that I have always said is that I can do most things that anyone else can do, I just do it a little differently and it doesn't make it better and it doesn't make it worse. (3.3, 92-96)

Emily's perspective of disability resonates not only with the perspective of Do and Geist (2000), but also with the views of Fleischer and Zames (2011), Pfeiffer (2001), Stone (2005), and Valeras (2010). Valeras (2010) trenchantly observed:

> Persons with a hidden disability…may feel that they fall on the spectrum between disabled and nondisabled. Conceptualizing ability and disability as a continuum is unsupported by both the disability community and nondisabled people. (p. 10)

Stone (2005) also expounded further upon the "hegemony of dualistic thinking" (p. 294) governing able-ism that further challenges persons with invisible disabilities:

> The hegemony of dualistic thinking means that there is the assumption of an unproblematic divide between disabled/ abled. Coupled with the belief that decisions about who belongs in which category can be determined with empirical evidence, there is no room for recognizing that those who appear to be abled may nevertheless have unseen difficulties. (p. 294)

In her qualitative study, Stone (2005) explored the reactions of others to young, female stroke survivors and the impact of such reactions on these survivors' quality of life and social environment. Similar to the experiences of Emily, who was confronted with others' astonishment at her young age of living with a long-term disability, the participants in Stone's (2005) study also felt a need to "continually explain themselves to others" (p. 300) as "their apparently able bodies led others to have expectations of them they could not meet" (p. 300). However, unlike the participants in Stone's study who had to adjust to living with a permanent, static disability, Emily has had the additional challenge of navigating the uncertainty inherent with a permanent disability that progressively deteriorates and changes over time.

Even without drawing upon a formal, clinical definition of disability to apply to her personal experience, Lynn also identified her experience of living with unexplained fertility as disabling:

> I do consider it to be a disability for the reason that to me it has felt very much like my body has not been able to do what other female bodies can do very naturally and I don't know what the clinical definition of disability is or anything like that, but it certainly has felt disabling to have this condition. It has felt unbelievably invisible at times…(4.3, 6-9)

Lynn's insights support the premise forwarded by Valeras (2010) that "disability…is an identity category any person can enter at any time" (p. 11). In addition, due to the constantly shifting etiology undergirding the working diagnosis of unexplained infertility, Lynn learned to release control of the process, and through that release, ultimately regaining a renewed sense of control.

> It was controlling me and now I feel like I can control, at least, all of it is so uncertain that I cannot control what happens at all and I think that I have accepted that, but I can control how I talk about it and how I respond to what people ask me about it. It just feels like a lot of this process for me has been about that idea of control because it is such an uncertainty and you never really know what is going to happen and you never really know what is wrong or why. A lot of it for me has been finding ways to reclaim a sense of control over what is happening to me. I think it is very unsettling to live in place where you don't feel like you have control over any of it. (4.2, 55-62)

Lynn's experience of regaining both a renewed sense of security and control in the face of an invisible condition is similar to the results reported by Jacobsson (2011) in participants' narratives that described the phenomenon of living with coeliac disease. These comprised "a constant movement between conflicting feelings" (Jacobsson, 2011, p. 23), including negotiating the following: (a) conflicting feelings of security versus insecurity across different situations; (b) conflicting feelings of control versus loss of

control; and (c) feelings of visibility and inclusion in contrast to feelings of invisibility and exclusion.

Sam's and Anna's self-perceptions of their respective conditions highlighted the complex, potentially overlapping terrain between chronic illness and disability, as noted by Edwards (2013):

> The relationship between illness and disability is equally complicated. Not everyone with a physical disability has a chronic illness, and not everyone with a chronic illness is considered disabled by his or her symptoms, but there is a lot of crossover. (Edwards, 2013, p. 52)

The lived experiences of Sam and Anna also provide support to the position of Wendell (2001) that "young and middle-aged people with chronic illnesses inhabit a category not easily understood or accepted" (p. 21). In addition, the vicissitudes in overt symptoms over time and place in both Addison's disease and multiple sclerosis, as experienced by Sam and Anna respectively, provide additional support for this earlier observation by Shakespeare and Watson (2001) regarding the nebulous demarcation between impairment and disability:

> While impairment is often the cause or trigger of disability, disability may itself create or exacerbate impairment. Other impairments, because invisible, may not generate any disability whatsoever, but may have functional impacts, and implications for personal identity and psychological well-being. (p. 18)

Sam renounced her condition of Addison's disease, a chronic illness, as a disability due to its current manageability through daily medications and due to its present lack of a negative impact upon her daily life. However, she did acknowledge that her concerns about its manageability might increase as she ages, namely in the season of her life when she may be "less in charge of her faculties" and potentially more at risk for age-related senility (1.3, 209). In addition, Addison's disease necessitates effective daily

management, as Sam observed that "it impacts you every day and it impacts every health situation that I have had since I was 26" (1.3, 27-28). Sam's perception of her present condition as a non-disability is consistent with the observation of Wendell (2001):

> Moreover, those of us with chronic illnesses do not fit most people's picture of disability. The paradigmatic person with a disability is healthy disabled and permanently and predictably impaired. Both attitudes toward people with disabilities and programs designed to remove obstacles to their full participation are based on that paradigm. Many of us with chronic illnesses are not obviously disabled; to be recognized as disabled, we have to remind people frequently of our needs and limitations. That in itself can be a source of alienation from other people with disabilities, because it requires repeatedly calling attention to our impairments. (p. 21)

Anna positively identified her lived experience of multiple sclerosis as a disability due to its chronic nature, the current absence of a cure, and its effect upon "all of life" (2.3, 84). In addition, Anna noted that the ubiquitous, constant presence of MS lingers with her even when she feels well, but she does not perceive the term disability to be stigmatizing:

> I definitely feel like the word disability fits for me. So, even when we first met, or even when I was hearing about your research, I was like, *I want to do that.* So, I definitely identify with it and with the invisible part of it. Even when I am feeling well, it feels like I have got this. It doesn't necessarily feel like a bad word. I don't mind it. It doesn't make me feel bad or anything. I think probably because it affects all of life. (2.3, 80-84)

Anna's sentiments further support Valeras' (2010) premise regarding the idea of bi-ability to supplant the extant "binary identity structure – either/or, disabled/nondisabled" (p.12) currently used to describe persons who have ability differences:

> [it] might be appropriate to look at persons with a hidden disability as bi-abled. Bi-abled people are a population that transforms their identity and needs depending on the situational context. With a foot in both the nondisabled and the disability worlds, they belong to both and fit completely into neither. Persons with a hidden disability serve to uphold the notion that the body is constantly evolving and changing and thus, the disability category is a fluid and porous one. (Valeras, 2010, p. 12)

In summary, participants' astute perspectives on disability support the emergent view of disability as a spectrum, with the very category of disability itself being dynamic. This contrasts with the traditional perspective of ability as a static, binary, and dichotomized category, with disability positioned as the stark antipode to ability (Fleischer & Zames, 2011; Pfeiffer, 2001; Stone, 2005; Valeras, 2010; Wendell, 2001). The lived experiences of participants in their respective journeys further illuminate the need for embracing chronic illness, including illnesses whose symptoms may fluctuate over time, within the purview of disability (Edwards, 2013; Wendell, 2001). Participants' embodied experiences also support the position of dismantling the stratified view of impairment and disability (Shakesepeare & Watson, 2001). With an eye towards integration, where embodiment facilitates this integration, disability and impairment may thus be viewed as different locus points on a continuum or merely as different facets of one experience (Shakespeare & Watson, 2001, p. 22).

Recommendations for Future Research and Practice

Introduction

This phenomenologically based study yielded rich narratives from each of the four participants through the process of focused in-depth interviewing and life-history interviewing. Each participant actively, patiently, and thoughtfully engaged in all the stages of the in-depth interviewing process. Notwithstanding the fruitfulness of the narratives shared by this study's participants, limitations of the study do exist. One limitation is the study's small sample size. As previously mentioned in Chapter 3, because of the study's very small sample size, results cannot be generalized to the

broader demographic of all women with disabilities. Social demographics of the study's participants comprise another limitation. College-educated, English-speaking, professional women from urban and suburban environments elected to participate in the study without the researcher specifically controlling for these factors. In addition to the researcher's affiliation with a university in an urban setting, it is possible that the complexity, length, and degree of information sharing involved with the in-depth interviewing process may have also been a potential barrier to engaging women from diverse backgrounds, potentially impeding the participation of women from a variety of socioeconomic, educational, linguistic, ethnic, and culturally diverse backgrounds.

Recommendations for Future Research

As Westhaver (2000) observed, "both phenomenology and feminism situate the personal in the research process" (p. 88). One could view the present study as a launching point for further phenomenological exploration of women's lived experiences with a range of hidden disabilities or chronic illnesses, including rare, chronic illnesses. One could also view the present study as a pilot study to inform the broader design of epidemiologic research that focuses upon a specific hidden disability or chronic illness, as experienced by women across different age groups, geographic regions, and cultural backgrounds.

Given the limitations of the present study mentioned above, the following recommendations for future qualitative research are made. It is recommended that additional phenomenologically-based research be conducted on the lived experiences of women with disabilities with a more limited, central focus on a particular hidden condition (e.g., autoimmune diseases or rare disorders) or a specific hidden disability

(e.g., non-age related infertility or non-age related progressive macular degeneration). This research could potentially explore emergent themes arising from this study. Such themes include the following: (a) the liminal and permeable boundary between disability and chronic illness; (b) the limitations of current constructs of disability to adequately describe the lived experience of a non-visible disability, and (c) the role of non-discursive, material factors, such as economic, social, and institutional structures, that contribute to contemporary contours of women's lived experiences with hidden disabilities. Regarding the latter, it is recommended that a material feminist lens be used to further identify, gauge, and calibrate the impact of socio-structural barriers upon the contemporary experiences of women with hidden conditions.

Secondly, it is recommended that future studies actively endeavor to include women with hidden disabilities from diverse cultural, linguistic, and socioeconomic backgrounds in the United States. Participants in this study resided in urban or suburban settings in coastal areas of the West Coast or East Coast of the U.S. Future research in the experiences of women with non-visible disabilities who reside in non-urban or rural settings, as well as in non-coastal areas of the U.S., is critically needed.

Finally, it is recommended that future research replicate the design of this study to explore the lived experiences of women with hidden disabilities in a country, or countries, outside the United States. The results from such a study would add to a needed corpus of data to inform a more robust dialogue centering on international disability rights from a gendered perspective.

Recommendations for Future Practice

Recommendations for future practice will draw upon principles and precepts

delineated within the epochal United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD), the first global human rights treaty specifically addressing the rights and needs of persons with disabilities (United Nations & Secretariat for the Convention on the Rights of Persons with Disabilities, 2012; Garland-Thomson, 2011). This treaty includes several sections, including its Preamble and Article 6, that specifically focus upon women with disabilities. The UN-CRPD is thus utilized as a canonical reference around which recommendations are framed and directed in this section.

In the groundbreaking Preamble of the UN-CRPD, disability is innovatively construed as a non-static concept, premised upon the social model of disability. In addition, material interactions are addressed in terms of potential barriers arising from social attitudes and environmental factors, rather than endogenous factors:

> Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis. (General Assembly of the United Nations, 2006, Preamble (e))

The novel concept of disability as an evolving process is to be applauded, as it sets the stage to further deconstruct the binary dialectic of ability and potentially allows for a flexible concept of disability as a spectrum. However, in order to better encompass the entire experience of disability, it is recommended that the Article's definition of disability be further expanded to specifically include the following: interaction between the person with impairment(s) and her own body, including endogenous, non-visible factors, such as pain, numbness, and fatigue. Both endogenous and exogenous, environmental factors are elements in material interactions between a person with a disability and potential barriers to equity and equality in society. Invisible endogenous

factors may function as agents of marginalization and exclusion as much as external social attitudes toward visibly differentiated bodies.

In addition, the first article of the UN-CRPD holds persons with disabilities to be the following:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (General Assembly of the United Nations, 2006, Article 1)

It is recommended that the definition of persons with disabilities be expanded to include those with physiologic impairments. Autoimmune disorders, infertility, and adrenal insufficiency are a few examples of physiologic impairments. It is also recommended that a separate sentence or phrase be added to explicate that such impairments may be hidden, invisible or non-perceptible to the naked eye. In addition, it is recommended that a third sentence or phrase be added to the existing definition to illuminate the fact that some disabilities may manifest themselves as short-term or temporary, even though the actual impairment itself is permanent. Two relevant examples are the vicissitudes in symptoms of multiple sclerosis, as well as the debilitating, life-threatening symptoms of an Addisonian crisis.

It is recommended that articles within the UN-CRPD focusing upon awareness-raising (Article 8) and health (Article 25) be expanded to specifically address the import of sensitivity training for medical and allied health professionals who are directly involved with diagnosing and treating women with long-term, chronic illnesses or conditions that could result in short or long-term disability. Professional training is addressed by the CRPD in the Convention's "General obligations":

> To promote the training of professionals and staff working with persons with

> disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights (General Assembly of the United Nations, 2006, Article 4. 1(i))

Sensitivity training for medical and allied health professionals logically connects to Article 8, which focuses upon awareness-raising and which already asks States Parties "to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life (General Assembly of the United Nations, 2006, Article 8.1 (b)). The need for such training also connects to Article 26 of the CRPD, which focuses upon habilitation and rehabilitation. This Article stipulates that "State Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services" (General Assembly of the United Nations, 2006, Article 26.2).

The United States has signed, but not yet ratified, the UN-CRPD. On November 5, 2013, the U.S. Senate Committee on Foreign Relations commenced hearings on the UN-CRPD. Even though the U.S. is not yet legally bound to comport with the principles of the UN-CRPD, it is recommended that individuals, government agencies, public and private healthcare institutions, businesses, corporations, not-for-profit organizations, and community agencies within the U.S. look toward the UN-CRPD for best practice guidelines in order to improve and enhance inclusive conditions for women with hidden disabilities at the regional, local, state, and federal levels.

Contributions

This study contributes to the limited corpus of literature on women with disabilities, including the emergent literature documenting the experiences of women with hidden disabilities (Depauw, 1996; Garland-Thomson, 2004; Stone, 2005; Sturge-

Jacobs, 2002; Taylor, 2005). More specifically, within the scope of feminist disability scholarship, the results of this study further contribute to the germinal literature documenting the lived experiences of women whose conditions may asynchronously fluctuate in visibility across time, such as multiple sclerosis (Vick, 2007, p. 2). This study also strengthens the broader discourse regarding the permeable boundary between chronic illness and disability, as well as the porosity between ability and disability, with a directed eye toward the view of disability as a spectrum (Edwards, 2013; Fleischer & Zames, 2011; Pfeiffer, 2001; Stone, 2005; Valeras, 2010; Wendell, 2001).

Results of this study also throw new light upon a frequently cited limit of the social model of disability, namely the social model's explicit rejection of the notion of impairment (Crow, 1996; Oliver, 2009; Taylor, 2005). In rejecting impairment, the social model of disability, most recently canonized in the iconic United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD), limits itself from capturing the entire disability experience, particularly as experienced by those with invisible conditions characterized by fluctuating, non-visible symptoms, such as pain, numbness or fatigue. Results from this phenomenologically-based study support the earlier view posited by Wendell (2001). According to Wendell (2001), through a focus on "the phenomenology of impairment" (p. 23), it is possible to acknowledge impairment without abandoning the fundamental premises of the social model of disability. In addition, the examination of the phenomenology of impairment also allows for the inclusion of chronic illnesses under the disability rubric (Wendell, 2001, p. 23). Without completely abandoning the social model, this study's results further speak to the

heterogeneity of impairments and the subsequent, differential impact of impairment upon individuals as observed by Asch (2004):

> Persons with characteristics such as diabetes or asthma that may not be readily observable may sometimes find that their impairments affect a given set of activities and life decisions, whereas at other times they find life flowing smoothly with no thought to their medical label…My point here is that impairments impinge upon people differently from one another depending upon a host of psychological and social factors that all are external to the biomedical condition. (pp. 18-19)

Results from this study further contribute to the recent, emergent literature in material feminism that examines interaction between bodies, each of which has differentiated shapes and capabilities, with the diverse components of the external environment (Garland-Thomson, 2011, p. 594). These components, beyond the materiality of a human body, included factors typically categorized as social, economic, natural, physical, geopolitical, and biological (Barad, 2008, p. 128). The illumination of all of these factors in participants' narratives throws a concentrated spotlight on the paramount importance of the right to health, a human right succinctly summarized in Article 25 of the Universal Declaration of Human Rights (UDHR):

> Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
>
> (United Nations General Assembly, 1948, Article 25.1)

The right to health care is a social and economic right not yet fully recognized as a human right within the United States. As Farmer (2010) noted, the principles of Article 25 of the UDHR "are actionable, at least on a small scale and almost surely on a much larger one, if we can afford the rhetorical tools necessary to bring the privileged on board as we build a movement to promote the rights of the poor" (Farmer, 2010, p. 519). With

regards to access to critical resources such as health care, all participants in this study had access to necessary health care through their employment. Given the challenges that participants articulated regarding the paternalistic attitude that they encountered in their interactions with the medical establishment, it can only be surmised that these challenges may be amplified logarithmically for those without access to health care or the socio-economic capital that full-time employment affords.

The results of this study augment the corpus of counter-narratives that deconstruct mainstream assumptions of what it means to be "whole." As Connor (2008) has astutely observed:

> People with disabilities and people of color have historically been positioned not only as inferior to nondisabled, White counterparts, but they have also been portrayed as not quite "whole." … Thus, counter-narratives challenge hegemonic knowledge and understandings, providing epistemological insights unknown to majority groups. (Connor, 2008, pp. 458-459)

While participants did not articulate specific challenges arising from race or class, all participants spoke to experiences of alterity, specifically experiences of being "othered" or being part of a minority, as a result of their journey through disability. In the narratives of this study's participants, the interaction of endogenous and exogenous factors contributed towards feelings of inclusion, marginalization, and exclusion, as well as towards the rhizomatic formulation of meaning-making arising from these interactions. Prominent exogenous factors comprised the role of technology, socio-cultural expectations associated with gender, and economics. Endogenous factors included the particular impairment in conjunction with its invisibility, as well as age. The articulation of both exogenous and endogenous factors in the lived experiences of this study's

participants comports with Garland-Thomson's novel concept of fitting and misfitting, drawn from a materialist feminist perspective of disability:

> The idea of a misft and the situation of misfitting I offer here elaborate a materialist feminist understanding of disability by extending a consideration of how the particularities of embodiment interact with their environment in its broadest sense, to include both its spatial and temporal aspects…the concept of misfit emphasizes the particularity of varying lived embodiments and avoids a theoretical generic disabled body that can dematerialize if social and architectural barriers no longer disable it. (Garland-Thomson, 2011, p. 592)

In redefining disability through dialogue, discourse, and reflection upon lived multi-dimensional experiences, including the intersectionality of gender and disability, participants created new spaces for a "social location complexly embodied" (Siebers, 2011, p. 14). These spaces of intersectionality afforded "the contemplation of ways in which numerous discourses together create multidimensional experiences, complicating notions of how people come to know, and understand their lives" (Connor, 2008, p. 470).

Closing Comments

In the words of Garland-Thomson (2011), "our bodies are also the agents of our lived experience and subjectivity. An embodied engagement with the world is in fact life itself" (p. 600). Through embodied engagement with this study, this beginning researcher has gained a profound appreciation for the courage, sagacity, and resilience of the women who volitionally elected to participate in this study. Just as all four participants in this study articulated the shared leitmotif of the transformational impact of living with a hidden condition or disability, this researcher has also been transformed by the powerful stories that these participants shared through the in-depth interviewing process.

This study unfortunately cannot eradicate all existing barriers that impede the full realization of ability and potential for women with invisible disabilities. However, it is this beginning researcher's hope that privileging the voices of four women with hidden conditions will contribute towards the collaborative creation of a more inclusive space, space where ongoing dialogue regarding what it means to live with a hidden disability as a woman in contemporary society is heard, acknowledged, and validated.

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APPENDICES

APPENDIX A: INFORMED CONSENT FORM

INFORMED CONSENT FORM

UNIVERSITY OF SAN FRANCISCO

CONSENT TO BE A RESEARCH SUBJECT (PARTICIPANT)
in a DISSERTATION STUDY

Purpose and Background

Ms. Michelle Yee, a doctoral student in the School of Education at the University of San Francisco, is conducting a phenomenologically-based study of women with "invisible" disabilities in the United States (U. S.) for her doctoral dissertation research.

I am being asked to participate because I am an adult female with an invisible disability.

Procedures

If I agree to be a participant in this study, the following will happen: I will participate in a set of three interviews with the researcher, during which I will be asked about my life and work experiences in the U.S. Each interview will be a maximum of 90 minutes in duration and will be conducted in a private setting selected by the subject. These interviews will be audio-recorded for later transcription.

Risks and/or Discomforts

1. It is possible that some of the questions addressing my "invisible" disability may make me emotionally uncomfortable. However, I am free to decline to answer any questions that I do not wish to answer. In addition, I am free to stop participating in the project at any time.

2. Any participation in research carries the risk of loss of confidentiality. Study records, including audio and electronic data files, will be kept as anonymous as possible and password protected. No individual identities will be used in any reports, presentations or publications resulting from the study. Use of pseudonyms will also be used to protect participants' identities.

3. Because the time required for participation in this project may involve a set of one-to-one interviews (maximum of 90 minutes of interviewing time per day) across a few days, there is the risk that I may become physically fatigued and/ or bored. To minimize this potential risk, rest breaks will be provided as needed in the course of conducting the interviews to allow for my maximum comfort. In addition, on any one day, the interview time will not exceed 2 hours (total) of interview time.

Benefits

There will be no direct benefit to me from participating in this study. The anticipated, but not guaranteed, benefits of this study may be the following:

a) Potential contribution to the existing corpus of ethnographic documentation on women with invisible disabilities

b) Increased self-understanding and self-empowerment through the narration of past experiences, namely the construction of narrative identity in relation to self identity

Costs/Financial Considerations

There will be no financial costs to me as a result of taking part in this study.

Payment/Reimbursement

I will not be paid or reimbursed for my participation in this study, excluding food and non-alcoholic beverages provided by the researcher during rest breaks.

Questions

I have talked to Ms. Michelle Yee about this study and have had my questions answered. If I have further questions about the study, I may call email her at: myee@stanfordalumni.org or Dr. Shabnam Koirala-Azad at skoirala@usfca.edu.

If I have any questions or comments about participation in this study, I should first talk with the researcher. If for some reason I do not wish to do this, I may contact the IRBPHS, which is concerned with protection of volunteers in research projects. I may reach the IRBPHS office by calling (415) 422-6091 and leaving a voicemail message, by e-mailing IRBPHS@usfca.edu, or by writing to the IRBPHS, Department of Psychology, University of San Francisco, 2130 Fulton Street, San Francisco, CA 94117-1080.

Consent

I have been given a copy of the "Research Subject's Bill of Rights" and I have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a student or employee at USF.

My signature below indicates that I agree to participate in this study.

Subject's Signature Date of Signature

Signature of Person Obtaining Consent Date of Signature

APPENDIX B: INTERVIEW GUIDE

Interview Guide

Interview #1

The first interview of the three-part series explored the process that led the participant into the realm of living with a non-visible disability. The researcher used the following as a general guide:

"Today, we will take some time to discuss your life experiences that led you to into the realm of disability, in particular the realm of a hidden disability. I would like you to take some time to retrace the steps in your life's journey that have led you to the point at which mainstream society began to formally identify you as a person with a disability (or a disabled person)"

3. Tell me the story of how you came to learn you had a non-visible disability.

Possible sub-questions:

a) When and how did you learn that you had a disability?

b) How did this discovery affect you?

c) What was the process of "formal diagnosis" and was it brief or extended in duration?

d) What challenges did you face during this period?

e) How did you cope with and overcome these challenges?

f) What were some unexpected sources of strength during this period?

g) If there were one to three words that you would use to describe this period, what would they be?

h) What aspects, incidents, and people intimately connected with this experience stand out for you?

i) What changes do you associate with this period/ experience?

i) What feelings were generated during this period?

ii) What thoughts stood out for you?

iii) What bodily changes or states were you aware of at this time?

If the participant has not yet brought this up, also consider exploring:

i) How did this experience affect significant others in your life?

ii) Were there particular individuals who influenced you during this period?

iii) Who were those who influenced you positively and how did they do so?

iv) Who were those who influenced you negatively and how did they do so?

v) Is there anything else that you would like to share before we close?

Interview #2

The second interview explored the participant's contemporary experience of living with a hidden disability. The researcher used the following as a general guide:

"Today, we will explore your contemporary, present experience of living with an invisible disability. I would like for you to share with me as best you can what it is like for you to live with a hidden disability."

1. Tell me the story of what it is like to live with a hidden disability. Please describe your present-day experience of living with a non-visible disability.

Possible sub-questions:

a) Please tell me about your daily experience of living with a hidden disability.

b) Please tell me a story that illustrates your daily experience of living with a hidden disability.

c) Please tell me the story of how your experience of living with a hidden disability has evolved over time.

i) What challenges have you faced?

ii) How did you overcome these challenges?

iii) Were there any epiphanies or turning points during your journey of living with a hidden disability?

d) Within the context of your experience of living with a hidden disability, please tell me about your relationships with others on a daily basis (e.g., family, friends, work colleagues, and others)

4. Is there anything else that you would like to share before we close?

Interview #3

The primary focus of the third interview explored what it means for the participant to live with a hidden disability. The researcher used the following as a general guide:

"Today, in our last interview, we will explore what living with a hidden disability means to you. This is a reflection on the experience of living with a hidden disability. I would like for you to share with me as best you can what it means for you to live with a hidden disability."

1. In light of our last two conversations (interviews), how do you understand the experience of living with a hidden disability in your own life?
    a. What sense does it make to you? Or not?
    b. Do you consider your condition to be a disability? Why or why not?
    c. How do you define disability?

2. What are your aspirations, expectations, and hopes regarding your future experience of living with a hidden disability?

3. Stepping back from your own personal story, what is your vision for the future of women who live with hidden disabilities?

4. Is there anything else that you would like to share before we close?